

EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE LIVING WITH A
LIFE-LIMITING ILLNESS

By

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by

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This document is dedicated to my mother, Betty Campbell.

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The number of research studies that have been published in the hospice and palliative care literature has increased over the past 10 years; however, there have been few African American participants in the research studies and no conceptual frameworks to synthesize the experience of African Americans living with a life-limiting illness at home. The purpose of this study was to delineate a conceptual framework to synthesize the experience of African Americans living with a life-limiting illness at home.

Symbolic interactionism was the theoretical framework used to guide the development of the conceptual framework and to provide the foundation for the grounded theory methodology used for data analysis. Thirteen people diagnosed with a life-limiting illness participated in the study. The data collected and analyzed were transcripts from 28 audiotaped interviews, clinical information from a chart review and the researcher's field notes. Case studies were developed from the data to provide a context to illustrate

and synthesize the experiences of the participants. Data analysis led to the discovery of the basic social psychological process of “Keeping Faith.”

“Keeping Faith” emerged as the basic social psychological process by which the participants found comfort, searched for meaning and defined themselves in their social context. There were three groups of strategies used in this process: connecting with family and community, connecting with God and connecting with Self. The findings suggest that religion and spirituality provide the foundation for the process of “Keeping Faith” and its strategies. The findings from this study could be used to improve the care of people receiving hospice and palliative care. Future studies are needed to explore the evolution of the process of “Keeping Faith” over the period of a life-limiting illness.

CHAPTER 1 INTRODUCTION

Statement of the Problem

The number of research studies that have been published in the hospice and palliative care literature have increased over the past 10 years; however, the researchers have largely ignored the subjective experiences of African Americans receiving hospice services at home. There have been few African American participants and no theory development to synthesize the experience of African Americans living with a life-limiting illness at home. The importance of honoring the experience of African Americans living with life-limiting illnesses has been powerfully illustrated by noted author Audre Lorde, an African American woman coping with the impact of her breast cancer diagnosis. Lorde (1980) wrote:

The woman... who came to see me in the hospital, while quite admirable and even impressive in her own right, certainly did not speak to my experience nor my concerns....Yet every attempt I made to examine or question the possibility of a real integration of this experience into the totality of my life and my loving and my work, was ignored by this woman or uneasily glossed over by her as not looking at the "bright side of things." (p. 56)

African Americans have been participants in studies that focused on dying in institutions (hospitals and nursing homes) (Gates, 1988; Engle, Fox-Hill & Graney, 1998). Although patients and their families have interacted with many types of health care providers during the course of an illness, the majority of the care for people living with a life-limiting illness has been provided at home (Strauss, 1994).

African Americans have also participated in studies in which people who were not terminally ill responded to hypothetical scenarios about death and dying (Kalish & Reynolds, 1981; Neubauer & Hamilton, 1990; Caralis, Davis, Wright & Marcial, 1993; American Association of Retired Persons [AARP Carolinas], 2003). A person diagnosed with a life-limiting illness is doing the real work it takes to manage an illness in his or her social context. Having subjects respond to hypothetical situations may not be the best method to capture the experience of living with a life-limiting illness at home.

Theory Development in End of Life Care

The human experience of people who are dying lends itself to inductive description and theory development. Qualitative research methodologies have been used to develop theories to synthesize the experience of people who are dying in institutions. However, these studies may have limited transferability to the care of African Americans dying at home.

The major limitations in this body of literature are: (a) no description of the ethnic or racial composition of the samples used to develop the theories; (b) the theories were developed to synthesize experiences of people dying in inpatient settings such as hospitals, nursing homes and inpatient hospices; and (c) the participants were responding to hypothetical situations (Glaser & Strauss, 1965; Glaser & Strauss, 1968; Kubler-Ross, 1969; Pattison, 1977; Copp, 1998; Leichtentritt & Rettig, 2000).

Grounded Theory

Johnson (1968) made an important distinction between borrowed theories (those developed from other disciplines and drawn upon by nursing) and unique theories (those derived from the observation of phenomena and asking questions unlike other disciplines). This study is an opportunity to use grounded theory to develop a unique

conceptual framework to add to the knowledge base for hospice and palliative care nursing. The term grounded theory is used to designate theory generation that is grounded in the data. The determination of problems, concepts and theoretical schema are made by examination of the actual empirical social world rather than by working with a simulation, model or a picture of the world that conforms to the dictates of some pre-ordained schema (Harris, 1996).

Grounded theory is especially useful when little information is known about a phenomenon and few adequate theories exist. This method, with its theoretical framework of symbolic interactionism, is an ideal way to study people who are living with a life-limiting illness. The foundation of this framework is based upon individual meaning and unique interpretation of experience (Bowers, 1989; Hutchinson, 1999).

The major premises of symbolic interactionism are: (a) human beings act towards things on the basis of the meanings those things have for them, (b) meanings arise out of interaction of the individual with objects and the social world, and (c) the meanings arise out of the process of interaction between people or objects. Actions of others are instrumental in the formation of the meaning for any given object (Blumer, 1969).

Each person initiates an interpretive process when there is an interaction with the social context or social environment. This process is an active, dynamic process of formulation, reconsideration and revision in response to the environment. The identification of the context is very important because the interpretive process is initiated in response to conditions in a specific context (Hutchinson, 1999).

Significance of Theory Development for Nursing

Theory development in nursing started because of the mandate to demonstrate a distinct body of nursing knowledge. At this time it is imperative that palliative care

nursing develop theory to provide a foundation for our practice (Walker & Avant, 1995; Farrell & Funk, 1996). Nurses should be concerned about the lack of theory development based on the experiences of African Americans for three reasons. First, the lack of theory development has left nurses without a framework to organize recurring themes and issues in palliative care. Such a framework provides a format to facilitate discussion with other nurses about the experiences of African Americans who are dying and how these experiences compare or contrast with the others receiving hospice care.

Secondly, theories that have been developed from samples that are predominantly white or where the researcher has not described the ethnic composition of the sample may not be appropriate to use as the foundation for the care of African Americans living with a life-limiting illness (Walker & Avant, 1995). Boutain (1999) wrote, “generation of knowledge about African Americans using theories that are not tailored to or suitable to their concerns is unacceptable (p. 44).”

Third, nurses have not been able to contribute concepts to the state and national efforts to increase the number of African Americans using palliative care services. The literature contains many anecdotal and research articles describing barriers to access to palliative care, but there is little research focusing on the subjective experiences of African Americans who are living with a life-limiting illness (Gordon, 1995; Gordon, 1996; Jackson, Schim, Seely, Grunow & Baker, 2000). Concepts from theory development can be integrated into the outreach programs and may increase the number of African Americans who choose palliative care services. (Boutain, 1999; Engle et al., 1998).

Purpose

In summary, research that has explored the end of life experiences of African Americans has focused on people dying in institutions or the researcher has asked the subjects to respond to hypothetical scenarios. There appear to be no studies designed to develop theory to synthesize the actual experience of African Americans living at home with a life-limiting illness.

The purpose of this study is to delineate a conceptual framework that describes the experiences and processes of African Americans living with a life-limiting illness. The research study was guided by the following questions:

1. How do African Americans who have been diagnosed with a life-limiting illness describe their experiences living with their illness?
2. What is the basic social psychological problem that they share?
3. What is the basic psychological or sociological process used by people living with a life-limiting illness to manage that problem?

Definition of Terms

Life-limiting illness. A life-limiting illness is a disease for which the physician has certified that a person has a life-expectancy of 6 months or less. The life-expectancy of six months or less may also be documented by the presence of one or more of the core and disease-specific indicators for congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) that may be used to predict mortality within approximately six months or are parameters that may indicate the lowest survival rates (National Hospice Organization, 1996).

Hospice. The hospice philosophy is a comprehensive, holistic model of care that is designed to meet the needs of people diagnosed with a life-limiting illness and to provide emotional and spiritual support to their families. Hospice is a benefit covered under the

Medicare program and the Medicare Hospice Benefit (MHB) reimburses a hospice program on a per diem rate to provide clinical services, medications, equipment and supplies that are related to the care of the life-limiting illness.

Veterans administration home-based primary care. Veterans administration home-based primary care is a nurse-practitioner-directed program that provides patient care and case management services to homebound veterans living within a fifty-mile radius of Veterans Administration Medical Centers in north central Florida.

CHAPTER 2 REVIEW OF THE LITERATURE

Theories of End of Life Care

Copp (1998) has identified two major categories of theories of death and dying: stage theories and task-based theories. Copp's typology will be used to organize this portion of the literature review. The stage theories that will be presented in this review of literature will be the theories of Kubler-Ross (1969), Glaser & Strauss (1965), Glaser & Strauss (1968) and Leichentritt & Rettig (2000). The task-based theories that will be presented are the theories of Pattison (1977), Copp (1998) and Byock (1996).

Stage Theories

Kubler-Ross's five-stage model (Kubler-Ross, 1969) is commonly recognized as one of the seminal theoretical frameworks in death and dying. This theory is significant for four reasons: (a) the theory was one of the earliest inductively derived theories about individual reactions to diagnosis of life-limiting illness, (b) this model introduced theory to the general public and health care professionals, (c) it initiated the debate about death and dying in the U.S. and (d) the theory was identified as a catalyst for the hospice movement (Siebold, 1992).

The stages of the theory are anger, denial, bargaining, depression and acceptance. The theory explains how a person adjusts to the diagnosis of life-limiting illness. One of the criticisms of the theory is that it is prescriptive; that is, it mandates the stages a patient must go through in a linear fashion. However, in the original book, Dr. Kubler-Ross (1969) stated, "these stages do not replace each other, but can exist next to each other and

overlap at times (p. 263).” Health care professionals have tried to narrow the experience into these specific stages. These attempts to use the theory as prescriptive may have resulted because this stage theory awakened the conversation about death and dying in this country and it was for many the first exposure to a systematic description of the death process (Copp, 1998).

Glaser and Strauss developed two grounded theories from the same data set that was developed from interviews in hospitals in the San Francisco Bay area. The first theory described how the social context in a hospital defined and interacted with dying patients. The second theory explicated the temporal features of dying in hospitals (Glaser & Strauss, 1965; Glaser & Strauss, 1968). The development of these theories is significant for three reasons.

First, they were among the first studies to use grounded theory as a research methodology and a strategy to develop theory. Secondly, the theories were developed during a period when health care was in transition and the parameters of life and death were changing. Prior to the 1960s, infections were the primary cause of death in the United States. Cardiopulmonary resuscitation and ventilator support were new technologies and the majority of people died at home. In contrast, the introduction of antibiotics, improved nutrition and immunizations extended life-expectancy and therefore a person was more likely to die from a chronic illness than from an acute infection. The use of life-sustaining technologies provided medicine with the ability to sustain people in conditions that would have been unquestionably fatal just a decade earlier (Alexander, 2000; Dorff, 1991; Brody, Campbell, Faber-Langendoen & Ogle, 1997).

Third, the researchers introduced the concept of social definition to the study of death and dying in a facility. The concept of social definition was explored by asking two important questions, “How do interacting people come to define themselves and others” and “How do they make redefinitions over time?”

Glaser and Strauss (1965) described four contexts of death awareness between staff and patients, changes in the structure of care for people in each context, and communication by patients and staff within the context. Closed awareness occurred when staff members were aware of the patient’s poor prognosis and did not disclose this to the person. Nursing and medical staffs engaged in activities to keep the secret. Suspicion awareness is seen as an unstable situation in which the patient begins to suspect and begins activities to confirm his or her suspicion. The staff counters these seeking activities with evasion, especially maintaining control of facial and body mannerisms when dealing with the patient concerned. This may evolve into the stage of mutual pretense when both the person and the staff choose to pretend that the person with the life-limiting illness is going to live.

When the staff and patient both know the prognosis, this context is still fraught with difficulty for staff, person and family. This stage gives rise to conflict when the person’s construction of the appropriate death differs from the family and health care providers.

Glaser and Strauss (1968) published a study on the dying trajectories of the subjects in their previous work (Glaser & Strauss, 1965). These trajectories were: (a) certain death at a known time, (b) certain death at an unknown time, (c) uncertain death but at known time when the certainty will be established and (d) uncertain death and an

unknown time when the question will be resolved. The findings of this study suggested that the person with the life-limiting illness and the clinical staff could work together to negotiate and to manage the trajectory of “certain death at an unknown time.” The limitations of Glaser and Strauss (1965) and Glaser and Strauss (1968) were that the theories focus primarily on the experience of the health care providers and the theories were developed from the study of social structures in an institution.

Task-based Theories

Theoretical perspectives on death and dying have also been conceptualized as task-based theories. Pattison (1977) built on the work of Glaser and Strauss (1965, 1968) by combining a stage theory and a task-based approach to suggest interventions for clinical staff that are providing care to people who are dying.

Pattison proposed the living-dying interval as time period occurring between the crisis knowledge of death and the point of death. The living-dying interval has three phases: the acute crisis phase, chronic living-dying phase and the terminal phase. The first task of the staff is to deal appropriately with reactions of the client in the acute crisis phase so that the person’s life does not disintegrate into chaos. The second task of the health care providers is to respond to the ways the person adapts to the chronic living-dying phase.

The third task is to enable the person to move into the terminal phase. The onset of this phase is often not precise but is seen to begin when a dying person starts to withdraw from the outside world. The major limitation of this model is that it does not take into account that dying people exhibit a wide variety of emotions and behaviors during the dying process.

Copp (1998) undertook a study from a nursing perspective using grounded theory methodology to focus on hospice patients' construction and management of their experiences in confronting impending death and on their nurses' experiences in caring for the individuals as they died. This prospective study of the lives of 12 hospice patients was also used to extend the work of Glaser and Strauss (1968) by focusing on the trajectory: certain death at an unknown time. This study developed a readiness to die conceptual map. A person could be in one pattern or mode at a time, or could change between modes depending on the physical condition of the person's body and the person's acceptance of imminence of their death. The study validated that patients with a life-limiting illness are active in managing their own illnesses that is distinct from the physiological processes that nurses and physician manage such as pain, dyspnea and endstage symptomatology.

Byock (1996) proposed a developmental model that conceptualizes the experience of dying well as an opportunity for personal growth, embodying a sense of enhanced sense of meaning and a sense of completion. It is a task-based theory that is suggestive, rather than prescriptive. It suggests developmental landmarks and tasks for the end of life. Some of the landmarks are (a) a sense of completion with worldly affairs, (b) sense of completion in relationships with community, (c) sense of meaning about one's individual life, (d) experienced love of self and others, (e) sense of completion in relationships with family and friends, (f) acceptance of the finality of life and (g) surrender to the transcendent. The landmarks are tools used to guide clinicians to

anticipate issues and support the patient to recognize opportunities if they choose to do so. This model was developed using subjects who were receiving hospice care primarily at home.

Leichtentritt and Rettig (2000) developed a theory that described the salient features of a good death as defined by Israeli elders. The model incorporated themes from three distinct time periods: (a) prior the physiological death, (b) the physiological death and (c) after the physiological death. This model included many of the same developmental landmarks as Byock (1996); but in contrast, the significance of this model is that it considers that a good death also includes the importance of acknowledging that after the physiological death people are concerned about how their values and wishes will be honored in a funeral or memorial service. The study also emphasized the concept of continuity. The concept of continuity validates that a person's life continues to influence others after death through the legacy he or she has created.

The existing theoretical models that have been developed to synthesize the experiences of people living with a life-limiting illness have contributed to knowledge base for hospice and palliative care. The theory developed by Dr. Kubler-Ross has been cited so frequently over the past thirty years that the initial power and significance of this work has been diluted. Researchers are still testing parts of the models developed by Glaser and Strauss (1965, 1968). Two of the theories listed in this literature review were developed from concepts from their work. However, they may have limited transferability to the care of African American living at home because the studies were developed in institutions (except for Byock, 1996) and the ethnic composition of the samples used to develop the theories were not identified.

Concepts in End of Life Care

African American Perspectives at the End of Life

Overall there is a life-expectancy for men and women born in the United States of 76.9 years. The life-expectancy is (a) White females (80.2), (b) Black females (75.5), (c) White men (75) and (d) Black men (68.6) (Centers for Disease Control, 2001). Blacks have a higher age-adjusted death rate for the top three causes of death heart disease, cancer, and stroke, when compared to Whites, non-Hispanic, Hispanic, Asian/Pacific Islanders and Native Americans in the years from 1996-1998 (Centers for Disease Control, 2000). The top four causes of death for African Americans are as follows: (a) heart disease, (b) cancer, (d) accidents and (e) COPD (Centers for Disease Control, 2000).

Kalish and Reynolds (1981) wrote, “ In the behavioral and social scientific studies the experiences of African Americans who are dying are absent. We can only posit that if Blacks had written their own history and anthropology, death might have been more discussed” (p. 94). This is still an accurate assessment as we enter the 21st century. There are few studies about death and dying that have focused exclusively on African American participants or in comparison with other ethnic groups. The studies that have been identified will be presented in the next part of the literature review.

Kalish and Reynolds (1981) conducted a seminal study that compared and contrasted the way that people in four ethnic groups thought about death, dying and grieving. African Americans living in an urban setting in the western part of the United States (US) were compared with Japanese-Americans, Mexican-Americans and Anglo-Americans in a community survey with face-to-face interviews, participant observation in death settings (ward of terminally ill, funerals, coroner's office) and in-depth interviews

with selected participants. The average age of all respondents was 47.3 years of age. The respondents (who were not terminally ill) answered hypothetical questions about a number of issues related to death and dying.

One of the concerns in the study was how to unbundle the origins of African American beliefs about death, dying and grief from four possible sources (a) African values and beliefs, (b) the imprint of the dominant culture, (c) values and mores of the socioeconomic class or (d) unique to being part of being Black in the U.S. The Black participants were found to affirm life even in the face of statistics about lower life expectancies and personal experience of death and loss, such as experiences of coping with the loss of family by violent death, accident and war (original data collection early 1970s).

In comparison with the other ethnic groups African American subjects (a) were least likely to be afraid of dying; (b) had attitudes about death that were most likely to be influenced by religion, including mystical experiences; (c) were most likely to prepare for death by taking out life insurance; and (d) the second most likely to have made funeral arrangements. The only cultural influence on end of life decision making was religion and mystical experiences.

Gates (1988) conducted an ethnographic study that compared the dying experiences of two groups of people with life-limiting illness: those who enrolled in a hospice program (inpatient and home) and people who were hospitalized, but not enrolled in hospice. This study was conducted in a large metropolitan area with a large Black population and there were nine African American patients in the study and 15 White patients. Comparisons were made between the African American and White participants.

The major difference between the African American and the White participants was that the Black participants were more disclosing about the importance of religious and spiritual support during illness and in their lives. In contrast, the White participants stated that while their spirituality is important, it is a private matter to share with family, friends and their own clergy, but not hospital staff.

The participants did not mention cultural factors related to care. However the researcher noted accommodations made by the staff of the hospice and hospital for dietary needs and to support a Black patient's need to have larger numbers of extended family members present during the dying process.

Engle et al. (1998) compared and contrasted the experiences of Black and White terminally ill nursing home residents (n=13). The participants in this qualitative research study reported their own experiences in six major areas: attitudes about dying, pain, nutrition, religion, caregiving, care receiving and coping. There were no differences in the areas of attitudes about dying, nutrition, caregiving, care receiving and coping. However, there were differences in experiences with pain management and religion.

African American residents consistently reported moderate to severe pain of prolonged duration, especially at night and were unable to receive pain medications. In contrast, White residents rarely reported pain and if they did, they reported that adequate pain relief was achieved. In the area of religion Black residents tended to have more fundamental/charismatic beliefs, yet both Black and White residents believed in (a) a trusting, positive, loving God; (b) a definite sense of right and wrong; (c) the Golden rule; (d) the importance of attending church and (e) having little or no fear of dying.

Caralis et al. (1993) studied the influence of race and ethnicity on end of life decision making. African American, Hispanic and Non-Hispanic white (NHW) participants completed a questionnaire that contained a series of scenarios and questions about their health care experiences and those of their family members. The participants were not terminally ill and 42% self-reported that they were in good health. The responses of African Americans were compared with the responses of Hispanic and Non-Hispanic white participants (NHW). The study results suggest that African Americans were less likely to agree with physician assisted suicide under any circumstances, more likely to want intervention even if the outcome was futile, found that quality of life was less important when compared with Hispanic and NHW participants and were more likely to select aggressive interventions than Whites, Hispanics or Asians. In a similar vein it has been suggested that in comparison with other ethnic groups African Americans are less likely to want to die at home (Kalish & Reynolds, 1981; Neubauer & Hamilton, 1990).

Cultural Influences on End of Life Care

Love (1996) introduces a possible cultural influence on end of life decision making: the experiences of Black Americans whose medical treatment was denied or delayed because of racism. The author presents a study that followed the myths surrounding the death of the famous African American physician, Dr. Charles Drew, who sustained injuries in a car accident and failed to receive appropriate treatment because of his race. Through the use of oral histories and document review of newspapers, books, and personal letters she studied the events surrounding Dr. Drew's death. Dr. Love writes that the mythology associated with Dr. Drew's legend is not literally true, but it reveals a large truth at the heart of African American culture: it demonstrates the

continuing psychological trauma of segregation and racism in American life (Love, 1996). The legend's existence highlights the fact that the history many people live is not what is learned in the history books, but what has been personally and indirectly experienced in relationship with family members and others in the community and what is passed down as folklore, art, music and other forms of cultural expression.

However, other authors posit that neither the historical legacy of social injustice and unequal treatment nor the spiritual perspectives of death and dying are predictive of an individual's choices for end of life care (Crawley, Payne, Bolden, Payne, Washington & Williams, 2000). Barrett (1995) suggests that the manner by which members of any given family handles death seems to depend on many factors: their cultural background; social, economic and political context; their individual psychology and their family history.

Scholars have been reluctant to generalize African American beliefs and customs about death because as Blacks have migrated and/or improved socioeconomic status they have generally taken on standards and mores of their new communities and social class (Barrett, 1995; Kalish & Reynolds, 1981). When people are preparing for their death they make take different routes on the journey that may be in the context of culture, but it does not necessarily mean that end of life decisions, such as a choice of a hospice program, are made on the basis of culture alone (Staton, Shuy & Byock, 2001).

The major limitation of studies about death and dying that have included African American participants is that few prospective studies included African Americans who are living with a life-limiting illness with the notable exception of the qualitative studies of Gates (1988); Wilson, Hutchinson and Holzemer (1997) and Engle et al. (1998). In

the other studies that identified African-participants, the subjects were not identified as terminally ill and were responding to hypothetical situations or questions (Kalish & Reynolds, 1981; Caralis et al., 1993; Eleazer et al., 1996; Neubauer & Hamilton, 1990; AARP Carolinas, 2003).

Comfort

Providing comfort is a key aspect of nursing care for people in advanced illness, and nurses are evaluated by the ability to provide comfort. However, the concept of comfort is broader than the relief of physical symptoms. Diverse conceptualizations of comfort appear in the literature, such as being or feeling fully integrated and a sense of wholeness within oneself and in relationship to the world (Arruda, Larson & Meleis, 1992); “At home”, feeling at home is to experience oneself as being present, as being part of and related to, as an experience of integrity (Rasmussen, Jansson & Norberg, 2000) and the state of an integrated whole body (Morse, Bottorff & Hutchinson, 1995). These definitions have the experience of integration in common but do not mention anything specifically about symptom management.

Another description of comfort in the literature is illustrated with a quote from a hospitalized Hispanic cancer patient in Arruda et al. (1992): “ One can get used to feeling pain but doesn’t get used to not being comfortable....I can be *comoda* in a very nice room, having many things, lots of attention, but this doesn’t make me comfortable (p. 391).”

Other components of comfort identified in the literature are normalcy, feeling good physically without signs or symptoms of disease, nurture (in relationship to giving, receiving, gratitude and appreciation), safety and control (Arruda et al., 1992). Common themes in the description of comfort are the experience of its opposite: discomfort;

(Morse et al., 1995; Duggleby, 2000); feeling of being fragile and unsafe; (Rasmussen et al., 2000; Morse et al., 1995) being isolated or alone to deal with the symptom (Rasmussen et al., 2000; Roberts, Thorne & Pearson, 1993). Comfort is a broader concept than symptom management and is an important part of the subjective experience of people living with a life-limiting illness. The studies that have been included in this review illustrate the importance of capturing the experience and descriptions of the person living with the illness rather than relying on evaluation by family and staff.

Hospice Care

Evolution of Hospice in the United States

The hospice movement in the United States (U.S.) began in the mid-1960s with the seminal work of Dr. Kubler-Ross and Dr. Cecily Saunders. Beginning in the mid-1960s the use of technology blurred the line between living and dying and during that time 53% of the deaths in the U.S. occurred in the hospital and other institutions (Glaser & Strauss, 1968). Dr. Kubler-Ross wrote of the experiences of people diagnosed with a life-limiting illness in a book that was widely embraced by the general public and health care professionals. In contrast Dr. Saunders and her work with St. Christopher's Hospice influenced the training of doctors and nurses and was instrumental in the development of the hospice concept in the U.S.

Inspired by lectures from Dr. Kubler-Ross and Dr. Saunders and visits to St. Christopher's Hospice, the interdisciplinary Yale Study Group discussed end of life care in the community and completed a community survey to have a better understanding of end of life issues in the late 1960s. The work of Dr. Saunders, Dr. Kubler-Ross and the Yale group, among others, led to the declaration that the poor medical care provided to people who were dying was a major sociological problem in the United States.

They supported the development of the hospice philosophy as an alternative to medical care provided by traditional biomedical practitioners in the hospital (Siebold, 1992; Paradis & Cummings, 1986).

The hospice philosophy is a comprehensive, holistic approach to care designed to meet the physical, emotional, social and spiritual needs of the person enrolled in the hospice program and the family, including major attention to effective symptom control and pain management. Effective symptom management can make exploration of other issues of a psychosocial or spiritual nature much easier. Life is affirmed and hospice interventions neither hasten nor postpone death. A component of hospice care is medical care, but the goals of the care are no longer to cure the disease and therefore the tension that may be inherent in maintaining futile treatment is removed. Hospice provides support and care for persons in the last phases of incurable disease so that they may live as fully and comfortably as possible (Lattanzi-Licht & Connors, 1995; National Hospice and Palliative Care Organization [NHPCO], 2003).

Medicare Hospice Benefit

The Medicare Hospice Benefit (MHB) was started in 1982 and forever revolutionized the practice and business of hospice care in the U.S. This legislation increased regulation, shifted what had been an alternative to traditional biomedical treatment to the mainstream and increased fiscal pressures to manage the prospective payment for all costs related to the terminal illness. The MHB created a mechanism to pay for hospice for people with a limited life-expectancy. The benefit pays hospice programs a per diem rate to cover the services of the hospice clinical team and the cost of medication, equipment and supplies that are related to the hospice illness.

The hospice model of care requires that two physicians certify that the person enrolled in hospice has a life-expectancy of six month or less. Hospice care and its financial benefits cannot start without this certification. Additionally this legislation mandates that 80% of total patient days must be provided at home.

The person who enrolls in hospice must agree to palliative care rather than curative treatment. An interdisciplinary team comprised of physicians, nurses, social workers, home health aides, volunteers and clergy provides hospice care. The registered nurse coordinates the majority of the direct care services, helps the family and other team members to interpret symptoms and provides patient and family education. The nurse can also facilitate increasing the intensity of direct patient care services, especially as death approaches. (Moore & McCullough, 2000).

Hospice Statistics

The most recent statistics describe the primary diagnoses, age range, average length of stay and gender distribution of people enrolled in hospice programs in the United States. The majority of people enrolled in hospice have cancer diagnoses (53.6%). However, the number of people with non-cancer diagnoses has increased. The top five non-cancer diagnoses are (a) Endstage heart disease 10%, (b) Dementia 7%, (c) lung disease 6%, (d) Endstage kidney 3% and liver disease, 2% (NHPCO, 2003).

The age range, average and median length of stay and gender distribution are (a) approximately 78% of the people enrolled in hospice are 65 or older and 53.1% are 75 years of age and older; (b) the average length of stay for people enrolled in a Medicare-certified hospice program is estimated at 51 days and the median length of stay is 26

days, (c) 77% percent of people enrolled die within 6 months and (d) 55% of patients are female and 45% are male (NHPCO, 2003; Dunkle, Kart & Luong, 2000; Moore & McCullough, 2000).

One the major concerns about the hospice movement is lack of ethnic diversity of the people enrolled in hospice programs. It has been suggested that the conditions of participation of the MHB have been a barrier to access for minorities. (Bly & Kissick, 1994; Gordon, 1995; Gordon, 1996). The people served by the early hospice programs were predominantly white, middle-class people with cancer diagnoses and a stable support network in the early days of the movement (Buckingham & Lupu, 1982). The early participants in hospice were looking for an alternative to traditional biomedicine. However, African Americans in the early 1970s were not looking for an alternative to mainstream medicine. They were looking for equal access to the technology and facilities of biomedicine. The National Hospice and Palliative Care Organization estimated in 2003 that the ethnic diversity of the people receiving hospice services was 82% White, 8% African American, 3.4% Hispanic and 1.6% other ethnic identities and 4.8 with ethnicity unknown (NHPCO, 2003).

Symptom Management

Hospice research has focused primarily on symptom management by using descriptive studies. Weitzner, Moody and McMillan (1997) described the physical, psychosocial and functional symptoms that had been documented with highest frequency in hospice patients. The most common physical symptoms are pain (Herman & Looney, 2001; Duggleby, 2000; Letiza, Shenk & Jones, 1999; Weitzner et al., 1997), dyspnea (Herman & Looney, 2001; Webb, Moody & Mason, 2000; Roberts et al., 1993) and constipation and urinary elimination (Weitzner et al., 1997).

The major limitation of symptom management research is that it focuses on one aspect of the experience, the symptoms and not on the totality of the experience of living with a limited life-expectancy. The studies cited in this literature review focused on individual symptoms separate from the full context of the life of the person with life-limiting illness. People rarely have one physical or psychological concern. They are usually a combination of concerns (Duggleby, 2000; Weitzner et al., 1997; Staton et al., 2001). Herman and Looney (2001) suggested that people who are dying have on average 7 physical symptoms.

A weakness in the quantitative studies that have described physical symptoms in this review of the literature is that data have been collected from retrospective chart reviews, usually after the death of the person (Weitzner et al., 1997; Webb et al., 2000; Herman & Looney, 2001) or collected information from caregivers (Letiza et al., 1999).

In contrast, Roberts et al. (1993) triangulated data collection methods by using a quantitative tool, participant observation of the activities of patients and nurses and interviews with the patients. The study described the experience of late stage cancer patients with dyspnea and identified (a) that the presence of this symptom was a barrier to all aspects of daily life, (b) patients coped in isolation and (c) there was inconsistent understanding of the phenomenon by nurses. This study was the only one about symptom management that has suggested that patients use strategies distinct from those ordered by the physician or from nurse initiated interventions.

There are also studies that suggest that the experience of pain is broader than a physical experience. McMillan (1996) in a study of the impact of hospice on QOL found that pain factored on the emotional subscale rather than the physical. Duggleby (2000)

developed a grounded theory of pain in elderly hospice patients with cancer. The pain was found to have physical and psychological components. The etiology of the pain was from the cancer, other diseases, loss of physical functioning, feelings of helplessness and dependency. One of the weaknesses identified in that study was that it was difficult to study the experience of pain separately from the whole experience of the elderly hospice patient. A broader perspective on the experience of living with a life-limiting illness is found in the quality of life literature.

Quality of Life

The study of quality of life has come closest to exploring the full subjective, multidimensional experience of people living with a terminal illness, rather than focusing on symptom management alone. Moreover, the study of quality of life of people living with a life-limiting illness validates that terminally ill people are able to participate in research and illuminates the challenges faced by researchers who study this population.

Over the last ten years researchers have been studying quality of life (QOL) of people enrolled in hospice and palliative care programs for three purposes: (a) to evaluate quality of life as an outcome of palliative care provided at home or in facility-based care (Stewart, Teno, Patrick & Lynn, 1999; McMillan, 1996; Hardy, Edmonds, Turner, Rees & A'Hern, 1999; Tang & McCorkle, 2002), (b) to determine the impact that quality of life may have on the length of hospitalization after admission to hospice and (c) to describe the relationship between quality of life and the place of death for people enrolled in hospice programs (DeConno, Caraceni, Groff, Brunelli, Donati, Tamburini & Ventafridda, 1996; Smeenk, de Witte, van Haastregt, Schipper, Biezenmans & Crebolder, 1998).

Multidimensionality. Most researchers recognize that there is subjectivity and multidimensionality to QOL evaluation. Although the researchers rarely defined the concept of QOL in their studies, the concept was measured in quantitative studies as a multidimensional concept and the interview guides used by qualitative researchers also reflected multidimensionality. The five most common domains identified in the literature are physical, psychological, spiritual, social/role function and overall perceived quality of life (Haas, 1999; McMillan, 1996; Spiroch, Walsh, Mazanec & Nelson, 2000; DeConno et al., 1996; Wilson et al., 1997; Smeenk et al., 1998; Stewart et al., 1999; Thomson, 2000). Researchers captured multidimensionality in three ways: (a) by using factor analysis (McMillan, 1996; Smeenk et al., 1998), (b) by using tools whose items were already separated into domains or broad areas (Spiroch et al., 2000; Thomson, 2000, Wilson et al., 1997) and (c) using multiple tools to capture aspects of quality of life (Smeenk et al., 1998; Bretscher, Rummans, Sloan, Kaur, Bartlett, Borkenhagen & Loprinzi, 1999; DeConno et al., 1996).

Subjectivity. Subjectivity refers to the reliance on information received from the person living with the life-limiting illness. The studies of quality of life reported data from the person enrolled in a hospice or palliative care program using questionnaires, visual analogue scales and interviews (Bretscher et al., 1999; Smeenk et al., 1998; DeConno et al., 1996; Wilson et al., 1997; Spiroch et al., 2000). Only in a rare instance were data collected from family members or members of the health care team (McMillan, 1996; Bretscher et al., 1999). In the studies where quality of life was evaluated by family or members of the health care team, the quality of life score of the person enrolled in hospice or palliative care was correlated with the score of the family member or member

of the health care team. The findings were mixed: Bretscher et al. (1999) found that the scores of the patient and health care team were more closely correlated than the scores of the patient and family member. In a similar vein, McMillan (1996) found that there was low correlation between the quality of life evaluation of the patient and caregiver.

The conclusions about the impact of hospice and palliative care were inconsistent. Studies found that there was no change in quality of life during the period of hospice and palliative care (Bretscher et al., 1999; McMillan, 1996), there was an improvement in physical aspects of quality of life only (Smeenk et al., 1998) and there was an improvement in overall quality of life without evidence that any individual domain showed improvement (Hardy et al., 1999).

The inconsistent conclusions about quality of life may be due to a least two reasons. The studies that did not define the hospice or palliative care variable could not link specific outcomes to types and frequencies of services provided. There are many types of services that can be provided by programs as mandated by Medicare certification or on request of the family. Secondly, perhaps the dimensions measured did not capture all of the domains salient to the person living with a life-limiting illness.

Exploring racial and ethnic diversity will need to be built into future studies of quality of life to reflect the increasing diversity of people receiving hospice services. Only two of the studies listed racial or ethnic distribution of the participants (McMillan 1996; Wilson et al., 1997). Moreover, there were few qualitative studies despite the natural fit of qualitative methods to explore the subjective, multidimensional concept.

These studies have demonstrated that the hospice and palliative care population can participate in research studies, although there are many challenges. Many of the studies in

the review of literature mentioned issues inherent to the study of the vulnerable terminally ill population such as: (a) changing physical, emotional and cognitive status, (b) attrition from the studies due to decreased physical status, participant death and (c) the emotional nature of death and dying issues discussed in the interviews (McMillan, 1996; Hardy et al., 1999, Spiroch et al., 2000; DeConno et al., 1996; Wilson et al., 1997; Thomson, 2000). Also, in the study of quality of life Wilson et al. (1997) demonstrated that people in advanced stages of disease use processes and are able to articulate these processes to maintain, sustain and redeem quality of life.

Summary

The literature review included the following subjects in end of life care: theory development, African American perspectives at the end of life, cultural influences, hospice services and hospice research related to symptom management and quality of life. This body of literature has four major limitations: (a) there are few African American participants in end of life research studies, (b) African Americans were more likely to participate in studies where they responded to hypothetical scenarios about death and dying, (c) theory development is focused on the experiences of people who are dying in inpatient settings and (d) there is no theory development to synthesize the experiences of African Americans living with a life-limiting illness at home. The current study was conducted to contribute to the hospice and palliative care literature by identifying a conceptual framework that describes the experiences and processes of African Americans who are living at home with a life-limiting illness.

CHAPTER 3 METHODOLOGY

Research Plan

Setting

Hospice of North Central Florida (Hospice) is a Medicare-certified hospice program with an average daily census of 600 patients in a 17 county rural area in north central Florida. At the time of data collection the program was divided into seven patient care teams. Three teams are based in Gainesville: a team that provides direct patient care at home, a team that provides hospice services for residents in long term care facilities and a team that provides care at the E.T. York Hospice Care Center, an inpatient and residential care facility. Additionally, there are four satellite offices, one each in Palatka (Hospice of the Lakes), Lake City (Hospice of the Suwannee Valley), Trenton (Hospice of Tri-County) and Jacksonville (Hospice of Jacksonville). All are a part of the Hospice of North Central Florida Network.

Veterans Administration Home Based Primary Care (VAHPC) provides case management services to veterans who live within a 50-mile radius of Gainesville or Lake City. Nurse practitioners provide primary care in the home of veterans who are not able to travel to an outpatient clinic or hospital for primary care services.

Protection of Human Subjects

The proposal was submitted to and approved by the Institutional Review Board (IRB) at the University of Florida, Research Committee at Hospice of North Central Florida, Veterans Administration Subcommittee for Clinical Investigation (Gainesville)

and Veterans Administration Research and Development Committee (Gainesville) prior to the start of recruitment and data collection.

Sample Selection

In grounded theory research sample selection initially starts with purposeful sampling to find information rich cases to meet the informational needs of the study. The inclusion criteria were as follows: English speaking Black men and women who

- had a diagnosis of cancer, congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD)
- had a life-limiting illness as evidenced by the presence in the clinical record of either: the documentation of a physician's certification of a life-expectancy of six months or less or the documentation of one or more of the core and disease-specific indicators for CHF and COPD that may be used to predict mortality within approximately six months or are parameters that may indicate the lowest survival rates (National Hospice Organization, 1996).
- demonstrated the willingness to talk about their experiences living with their illness;
- were 50 years of age or older
- had the cognitive and physical status to participate in up to 2-3 interviews of 30-45 minutes in length over a period of a month. (The clinical indicators are presented in Figure 3-1. The disease specific indicators for CHF and COPD are presented in Figures 3-2 and 3-3 respectively).

Physical Decline and/or life-limiting conditions(s)
 Weight Loss > 10% over the past 6 months
 Multiple co-morbidities
 Serum Albumin < 2.5 gm/dl
 Dependence in most ADL's
 Karnofsky Score \leq 50%
 Need for frequent medical intervention/hospitalization
 Patient/family want supportive care
 Documentation that active curative treatment has ended and palliative care is now the goal of treatment

Figure 3-1 Core indicators. From "Medical Guidelines for Determining Prognosis in Selected Non-cancer Diseases," by The National Hospice Organization, 1996, *The Hospice Journal*, 11, pp. 47-59.

- I Recurrent congestive heart failure (CHF) with New York Heart Association (NYHA) Class IV symptoms in a patient on optimal diuretic and vasodilator therapy. Patients with Class IV symptoms are patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.
- A. Documentation of ejection fraction of 20% or less (not required if not readily available).
 - B. The patient experiences persistent symptoms of congestive heart failure despite attempts at maximal medical management with vasodilators and diuretics.
 - C. The patient is not a candidate, either by medical criteria or personal choice for a heart transplant, or re-transplant if he or she is rejecting a previously transplanted heart.
- II. Other factors that may decrease survival are as follows:
- A. History of cardiac arrest and resuscitation in any setting
 - B. History of syncope of any cause, cardiac or otherwise
- Basal systolic BP less than 120 mm Hg

Figure 3-2 Disease specific indicators for congestive heart failure. From "Medical Guidelines for Determining Prognosis in Selected Non-cancer Diseases," by The National Hospice Organization, 1996, *The Hospice Journal*, 11, pp. 47-59.

- Patients who fit the following parameters can be expected to have the lowest survival rates.
- I. Severity of chronic lung disease documented by:
 - A. Disabling dyspnea at rest, poorly responsive to bronchodilators, resulting in decreased functional activity for example: bed-to-chair existence, often exacerbated by debilitating symptoms such as fatigue and cough.
 - B. Progressive pulmonary disease as evidenced by: increasing visits to Emergency Department or hospitalizations for pulmonary infections and/or respiratory failure.
 - II. Documentation of physical signs of Cor Pulmonale (Right sided heart failure (RHF))-neck vein distention, peripheral edema, hepatomegaly
 - A. Resting tachycardia greater than 100 beats/minute
 - B. Unintentional progressive weight loss of greater than 10% of body weight over the preceding 10 months.

Figure 3-3 Disease specific indicators for pulmonary disease. From "Medical Guidelines for Determining Prognosis in Selected Non-cancer Diseases," by The National Hospice Organization, 1996, *The Hospice Journal*, 11, pp. 47-59.

Two groups of participants who met the inclusion criteria were recruited for the study to capture the variations in the experiences of people living with a life-limiting illness: people enrolled in hospice and receiving care at home and people who were enrolled in a home care program, but were not receiving hospice services.

Sample selection using the inclusion criteria initially yielded participants who had been in hospice for over six months at time of the first interview. After the first three participants completed their interviews, the researcher sought out people who had been in the program for less than six months. This was accomplished by seeking referrals from the admissions clinical team who are the first people to have contact with patient and families. This strategy enabled the researcher to interview people who had been in the program less than six months.

Recruitment

Recruitment and data collection were started with the hospice team in January 2003. After the proposal was approved as noted above, the researcher presented an overview of the research project to the hospice clinical teams in the satellite offices within a 50-mile radius of Gainesville. Hospice team members were asked to identify people who met the inclusion criteria and would be willing to participate in the study. After the first presentation, the clinical team requested a letter to be used by the staff to present the study to potential participants and their families (See Appendix D for Participant Recruitment Letter). The teams identified a contact person and the researcher contacted that person by phone every 2-3 weeks to see if there were referrals for the study.

Originally, participants with a life-limiting illness, but not enrolled in hospice, were to be recruited from another data collection site. There were no referrals from that

site from January 2003 to May 2003, and so negotiation began with the Director of the Veterans Administration Home-based Primary Care (VAHPC). Approval by the IRB and VA committees was granted in August 2003 and recruitment and data collection began with the VA participants in September 2003.

The researcher provided an overview of the project to the clinical manager at VAHPC prior to initiating data collection and left a copy of the patient/family letter for distribution to nurse practitioners providing care to patients within a 50-mile radius of Gainesville. The researcher called the nurse practitioners to request referrals for the study every 2-3 weeks.

At both sites, once a person was identified as meeting the study criteria, a clinical team member contacted the person about participating in the study and obtained permission for the researcher to call the patient's place of residence and to have the patient's contact information (name and phone number) given to the researcher. The clinical team members were asked only to identify and contact people who would be willing to participate in the study. The researcher obtained the informed consent.

All of the visits were made to the participant's home. If a primary caregiver was available, the caregiver was asked to be present in the home during the interview to meet the needs of the participant. The research protocol was reviewed with the participant and the caregiver, if available, prior to data collection. If the participant agreed to participate in the study, the consent form was signed prior to data collection. Verbal assent was sought at each interview to assure that the subject wished to continue with the study and agreed to be audiotaped. The participant was reminded at each visit that the interview and/or audiotaping could be stopped at any time and the participant could decline to

answer any question. People with a life-limiting illness can be viewed as a vulnerable population and every effort was made to be attentive to verbal and non-verbal communication, asking participants about their well-being and taking breaks as needed (Leichtentritt & Rettig, 2000).

Data Collection

Data collected for this study is as follows: a clinical chart review, audiotaped interviews, and researcher field notes. The chart was reviewed for documentation to confirm the primary diagnosis, symptoms or test results related to the primary diagnosis or the presence of the doctor's certification of the participant's life-limiting illness.

The interviews were 30-45 minutes in duration and there were one to three interviews per participant (The interview guide is presented in Figure 3-4). The first interview was the longest because it involved the informed consent process. The duration and number of interviews was based upon participant physical, cognitive and emotional status. Data collection was conducted at the homes of the participants living within a 50-mile radius of the university.

The sample was comprised of ten men and three women, ranging in age from 58-90 years. The average and mean age was 73.3 and 70 respectively. The primary diagnoses for the sample is as follows: seven of the participants were diagnosed with cancer, four with congestive heart failure (CHF) and two with chronic obstructive pulmonary disease (COPD). The participants completed 28 interviews over a period of 11 months.

Interview Guide

1. Tell me about your life?

Probes:

Where were you born?

What kind of work did you do?

How many children do you have

2. Tell me about your illness?

Probes: What is your diagnosis? When were you diagnosed? What did you hear the doctor say about your illness?

3. Think about living with your illness right now, what problems are of most concern or most distressing for you?
4. Describe how you spend each day.
5. What does being in hospice/homecare mean to you?
6. What would you like to have in your life today to make you feel better?
7. How would you describe your life?
8. What is the hardest thing about living with your illness?
9. How would you describe your quality of life right now?
10. What contributes to the quality of your life?
11. What is most important to you?
12. What would you like the last week of your life to be like?
13. What would you share with others going through this?
14. Is there anything else that you want to tell me about your experience with this illness and the way it is affecting your life?

Figure 3-4 Interview Guide. From "Salvaging Quality of Life in Ethnically Diverse Patients with Advanced HIV/AIDS," by H.S. Wilson, S.A. Hutchinson, & W.L. Holzemer, 1997, *Qualitative Health Research*. Questions 2-14 Used with permission of the author.

A transcriptionist transcribed the audiotaped interviews. The transcriptionist was given tapes labeled by the researcher with only the number assigned to the participant and the date of the interview. There was no identifying information released to the transcriptionist. The researcher added dialogue when the transcriptionist was not able to hear or to understand the aphorisms and references used by the participants. The transcripts were transcribed with focus on the spoken word. No effort was made to capture every feature of the conversation such as non-verbal sounds, length of pauses, or emphasis on certain syllables (Sandelowski, 1994).

Occasionally voices of family members or other background noise could be heard, but this was not transcribed nor was the person identified by name because these people had not consented. There were data that could not be transcribed because they were inaudible or unintelligible to transcriptionist and researcher.

Some of the tapes were difficult to transcribe due to mechanical difficulties, researcher inexperience with the equipment and physical/structural limitations of participants such as ill-fitting dentures, the absence of dentures and facial edema. One participant did not permit tape recording of his interview and so the researcher took notes during the interview and transcribed them after the interview as described by Patton (1990).

After each interview, the researcher typed field notes that included information about the setting of the interview, the participant's physical condition, response to the interviews and concluded with the researcher's reflections about the visit. The information collected from the interviews, chart review and field notes were kept confidential. The audiotapes were labeled with a number and date(s) of the interview.

The field notes were labeled in the same manner as the audiotapes. No other identifying information appeared on the tape or cassette case and upon completion of data analysis the tapes will be stored at the university office of the researcher.

The researcher kept a journal, field notes and a master file containing the names, diagnoses, addresses, phone numbers of the subjects, demographic data, tapes and original transcripts. The dissertation supervisory committee may have access to the audiotapes, field notes, the master file, original transcripts, and data analysis products. After the completion of the study the audiotapes, journal, field notes, the master file, original transcripts and data analysis products will be kept for three years in a locked file cabinet at the university office of the researcher.

Considerations for Research in Vulnerable Populations

Many of the studies in the review of literature mentioned issues inherent to the study of the vulnerable terminally ill population such as changing physical, emotional and cognitive status; attrition from the studies due to decreased physical status; participant death; and the emotional nature of death and dying issues discussed in the interviews (Spiroch, et al., 2000; Roberts, et al., 1993; Rasmussen, et al., 2000; Zlatin, 1995; Duggleby, 2000; Lambrindou, 2000; McMillan & Weitzner, 2003).

Discussion of death and dying issues may cause emotional upset or cause unanticipated issues to surface, therefore the research plan included a plan for contacting the hospice or home care staff for emergency follow-up (Kalish & Reynolds, 1981; Leichtentritt & Rettig, 2000). For hospice patients the procedure was: for interviews that were done Monday through Friday from 8 a.m. to 5 p.m., a team manager was to be called and the primary on-call nurses were to be called after 5:00 p.m. Monday through Friday, weekends and holidays to initiate follow-up as indicated; for Home Based

Primary Care patients the procedure was that for interviews that were done Monday through Friday from 8 a.m. to 4:00 p.m., the VAHPC office was to be contacted and after 4:00 p.m. the physician on-call in the Gainesville VA emergency room was to be called to initiate follow-up as indicated.

Data Analysis

The proofread transcripts, researcher field notes and the chart review data were the source for data analysis. The NVivo computer program was used to manage the transcribed data (QSR International, 2002). The process of data analysis in grounded theory is the constant comparative method that is concerned with generating and plausibly suggesting categories, properties and hypotheses about the data. There are four major steps used in the constant comparison method: (1) Open coding is the analytic process through which concepts are identified and their properties and dimensions are discovered in the data. Incidents and themes are compared from each interview and field notes with other incidents and themes from previous interviews, (2) Axial coding is the process of relating categories to their subcategories because coding occurs around the axis of a category integrating categories and their properties, conditions, causes, consequences. Axial coding begins the process of integrating the data that was analyzed during open coding. (3) Selective coding is the process of integrating and refining the theory and (4) Writing the theory is the last step in the process (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Sandelowski, 2004). The interview questions may be refined during the initial period of data collection and analysis (Bowers, 1989).

As the level of interpretation increases, the theory becomes more abstract. The data are saturated when no more new data or instances can be identified. The core variable or the variable that explains most of the process becomes the basis for emerging

theory. The researcher is looking for the basic social psychological process or basic social structural process that is linked to the core variable (Hutchinson, 1999; Sandelowski, Davis & Harris, 1989).

At this stage, the researcher also returned to the literature to compare and contrast initial data analysis from this study with extant literature and theory (Hutchinson, 1999). The literature was not used as data but rather to use the properties and dimensions derived from the literature to examine data from the study (Hutchinson, 1999; Gibson, 2000). After the initial data analysis and review of literature the interview guide was amended to add questions that explored the use of religion and spirituality while living with a life-limiting illness (Figure 3-5 contains the Religion/Spirituality Interview Guide).

During our interviews you have talked about (the researcher inserts one or more of the following topics as the basis for follow-up questions) as part of your religious/spiritual life

God's omniscience/omnipotence

Personal faith/belief

Talking with God

Prayer

Praise and thanksgiving

Church attendance

Bible reading

Other religious/spiritual themes:

Figure 3-5. Religion/Spirituality Interview Guide

Reliability and Validity

Researchers and people who wish to utilize research want to be assured of the trustworthiness and rigor inherent in quantitative and qualitative research. Quantitative researchers evaluate trustworthiness of a study by addressing issues of internal validity, external validity, reliability and objectivity. However, Lincoln and Guba (1985) have suggested the use of terms that are more consistent with the philosophy of naturalistic inquiry that is the foundation for qualitative research methodologies.

The naturalist equivalent for the positivistic terms internal validity, external validity, reliability and objectivity are credibility, transferability, dependability and confirmability, respectively. In quantitative research, assuring the internal validity of a study is one of the most important ways to demonstrate trustworthiness and rigor. Demonstrating internal validity is done to assure that the outcome of a quantitative study is due to the manipulation of the independent variable. There are many methods used to remove threats to internal validity, such as choice of study design, randomization in experimental designs and use of statistical analysis.

Qualitative researchers are not striving to control threats to internal validity for the same purpose as quantitative researchers. Qualitative researchers want to control threats to validity by including methods to assure trustworthiness and credibility. Credibility addresses whether or not the findings are credible to the research participants. Credibility will be assured by building into the protocol opportunities for the participants to review and comment on study findings and interpretations, where possible.

Two other important criteria of trustworthiness in quantitative research are applicability and generalizability. However, qualitative researchers are not striving to demonstrate statistical generalization or analytic generalization. In qualitative research

there is not the imperative to have control over the sample to make it statistically representative, to make the results generalizable. Yet the qualitative researcher wants to control a study's internal validity to build a strong study so that others may be able to use the findings.

Therefore, qualitative researchers are striving for transferability. The findings in qualitative research most often appear in the form of themes or a conceptual model (Sandelowski & Barroso, 2002). Questions are asked of the findings, "Can these findings be useful in other areas?" Transferability in naturalistic inquiry is a process that is initiated by the production of thick description in transcripts and data interpretation. This provides the reader enough information to reach a conclusion about whether transfer can be contemplated as a possibility. (Lincoln & Guba, 1985; Hutchinson, 1999).

The main premises of quantitative research focus on stability, control and predictability. Lincoln and Guba (1985) suggested that the focus on control and predictability is demonstrated by the ability to replicate a study. Hutchinson (1999) stated that the question of replication is not relevant in grounded theory development because the purpose is to develop new perspectives on a given situation, theory is modifiable and the belief in consistency is unrealistic in natural settings.

Providing the dissertation supervisory committee with the opportunity to review transcripts may enhance credibility and dependability. The dissertation supervisory committee will have access to the audiotapes, original transcripts, data analysis products, researcher's journal and field notes and may elect to audit this work product at any point during the process (Lincoln & Guba, 1985; Arruda, et al., 1992, Roberts, et al., 1993; Zlatin, 1995; Duggleby, 2000; Lambrindou, 2000; Leichtentritt & Rettig, 2000).

Study Limitations

Limitations in this study were having to rely on participants selected by the clinical team members, bias introduced by the physical and cognitive inclusion criteria, wide variation in the length of stay in hospice or home care program, limited opportunities to establish the credibility of study findings with participants and the limited geographical, religious and spiritual perspectives of the participants. A discussion of each limitation will be provided in the following paragraphs.

The research protocol required that the researcher seek recommendations from members of the clinical team about possible participants for the study and that the researcher could not access the clinical chart until the participant had signed a consent form. This procedure produced limitations in the study because researcher did not have access to all potential participants, but instead only to those thought by the clinical staff to be appropriate. Clinical staff have been identified as a threat to internal validity in end of life research due to their need to protect patients, their own biases about research and fear that this study may increase their workloads (Roberts, et al., 1993; McMillan & Weitzner, 2003; Sutton, Erlen, Glad & Siminoff, 2003).

Bias was introduced into the study by the inclusion criterion of requiring participants who had the cognitive and physical status to participate in up to 2-3 interviews of 30-45 minutes in length over a period of a month. It provided access only to people who had few physical limitations. Therefore, this criterion did not allow access to possible variations in the sample such as, but not limited to, people who were closer to death and had more physical limitations but were cognitively intact.

A wide variation in the length of time in the hospice and homecare program at the time of the first interview was another limitation in the study. For example, National

Hospice and Palliative Care Organization estimates that the median length of stay (LOS) is 26 days and the average length of stay is 51 days. (NHPCO, 2003), the LOS in both of the programs at time of interview ranged from 2 weeks to 5 years. Three of the hospice participants had been in the program for over a year at the time of their interviews. (Two of those had been in the program for 5 years.) One of the hallmarks of grounded theory is the identification of the properties of a process. A process can be described as a sequence of action/interaction occurring over a period of time (Strauss & Corbin, 1998). Mapping the temporal properties and making comparisons between people or within groups was difficult with divergent lengths of stay and 2-3 interviews completed over a period of a month.

The research protocol limited the number of interviews to three interviews due to concerns about physical and cognitive status of the participants, the need to let the participants know specifically what may be asked of them and the possibility that participants may not be alive for follow-up. Opportunities were lost to seek clarification and feedback from the participants who may have been able to give consent to participate in further interviews or telephone contact with the interviewer.

Finally, the participants in the study were African Americans living in rural communities in northern Florida. Religious and spiritual perspectives were based in Judeo-Christian religious traditions. Findings from this study may not be transferable to other African Americans with diverse religious and cultural experiences living elsewhere.

CHAPTER 4

LIVING WITH A LIFE-LIMITING ILLNESS

The interviews started by inviting the participants to share their life stories and illness journeys. Their narratives spoke of good things in their lives, such as love of family, a personal relationship with God and the belief in a life well lived. Some of the participants also spoke about painful situations in the present and the past such as the deaths of family members, the loss of a home due to a fire, incarceration of children, failings as parents and personal losses due to their illness. Yet, through it all they communicated the belief that they would continue to endure no matter what happened in their lives. This belief has been identified also in the work of another researcher who has studied death and dying beliefs of African Americans. Robert Kastenbaum (personal communication, 1972 as cited in Kalish & Reynolds, 1981) stated, “Our impression is that maintaining life has required so much energy, endurance and resourcefulness that they would not think of letting go just because things might get tough in one way or another” (p. 100).

Case Studies: Introducing a Context

Symbolic interactionism emphasizes the importance of the context, that is, the social, cultural or symbolic environment that surrounds a person (Bowers, 1989; Hutchinson, 1999). Mariano (1999) identified the construction of case studies as a method to present the environment that surrounds a person. The presentation of the context is important to the current study for three reasons. First, it will provide information on the worldview of people who are living in that context. This worldview

shapes how they define themselves and how they solve problems in interaction with the context. Second, the introduction of the context provides a vehicle to enter into the lives of the participants in the study and to connect with them on a personal level. Third, the context is important to people who may want to transfer the findings to other settings. Research studies done in one context may not be transferable to other contexts without a description of the environment of the study (Boutain, 1999).

The five case studies that are presented illustrate the experiences of African Americans living with a life-limiting illness. Each case study will include a brief biographical sketch, an overview of their illness journey as lived by the participant, my description of the encounters and reflections from the interviews. The biographical sketch was developed from the transcripts and my field notes and it integrates information from the lives of the participants that is separate from the illness. The overview of the illness journey was also developed from the transcripts and field notes and the overview describe the story of their illnesses up to the time of their interviews with me. The description and reflections will consist of my description of the participant and my thoughts during the research process. The names of the participants and the staff have been changed to pseudonyms to maintain anonymity. A summary of the concepts illustrated by the case studies will be presented at the end of the chapter.

Mrs. Proctor's Story: Honor Thy Father and Mother

Mrs. Proctor's story illustrates the power of affirming relationships through connections with ancestors, the community and the African American church. She used stories to describe the ancestors who she believed to be the source of her values and drew strength from the connection to her ancestors. Her story also illustrates that because of the relationships that she created with her students, she was provided with a home where

she was loved and honored. Although a primary caregiver is not a requirement for enrollment in hospice, the presence of a caregiver or a network of caregivers increases the likelihood that a person will be able to live at home.

Mrs. Proctor was recommended as a participant for the study by her social worker, Mary. Mary told me that Mrs. Proctor was very alert and eager to talk about her experiences. I called the home to make an appointment and spoke with Julia, her caregiver. Mrs. Proctor lived in a bright yellow house at the end of long, bumpy, rutted country lane. Julia met me at the door and talked with me about the purpose of the study. After the explanation I was escorted back to Mrs. Proctor's room. On the first visit to her room I did not see any medical equipment. I eventually realized that the small table that held her books, glasses and other personal items was an over-the-bed table that commonly accompanies a hospital bed. The hospital bed was in the corner covered with a multi-patterned quilt and an African American doll in the style of Raggedy Ann and Andy. On the wall across from the bed there was a formal picture of Mrs. Proctor, three fancy hats and a clear plastic frame holding a rose. Her electric keyboard was leaning against the wall. She wore a simple dress and covered her hair with a turban for the interviews. She always wore a watch and her wedding ring.

Biographical sketch. Mrs. Proctor was an 89-year-old retired music teacher. She had lived all of her life in the rural communities of north central Florida and the Florida Panhandle. She proudly told her history as the granddaughter and daughter of people who were enslaved. Her grandmother was born in Africa and brought to the Carolinas as a slave. She was a midwife and provided care to Blacks and Whites in her community. Mrs. Proctor's father was born enslaved and became a Baptist minister in his community.

At this time she is the only surviving member of her family of origin. She notes that while most of her family lived into their eighties, her mother lived to be ninety three and her grandmother, who was born in Africa, was estimated to have been between 112 and 114 years of age at her death.

Religious belief, church attendance, and the structure of the Black church have been a part of her life for as long as she can remember. Two of her brothers were ministers and she joined the church when she was 10 years old. At this time she is a mother in her local church. The church mothers are leaders in the congregation. They model appropriate behavior, provide feedback to the congregation in direct and subtle ways and serve as the moral compass for everyone in the church.

The belief in the power of education was another family value. She and two of her brothers became teachers and she completed a college degree at a time when it was unusual for a woman of any race to have a degree. She taught music in two communities in rural North Florida for 39 years and retired at age 79. At the time of her retirement she had been teaching in the community where she has lived for 28 years. She was one of the first African Americans to teach in her rural community after the schools were desegregated. She divorced her first husband and 24 years later married her second husband. He died in January 1995. She did not have any biological children with either husband. She has a niece in Leesburg who is her legal representative but is not actively involved in her day-to-day care.

Music was a large part of her life. She sang and played the piano. When she was teaching in the Florida Panhandle she would travel with a trio to Alabama and perform on the radio for fifteen minutes each week. She did not remember the name of the trio but

did remember the song they closed with, “Nobody Knows the Trouble I’ve Seen.” She also led and participated in various choirs with her students and in the community with adults. Using music as her ministry, she passed on some of her family values to her students. She taught life lessons such as the value of hard work, the importance of getting an education, respect for parents, that African American children should develop a variety of skills and the importance of learning history. She would learn how effective her lessons had been during the course of her illness.

Illness Journey. Mrs. Proctor’s description of her illness journey was focused on specific events and therefore the chronology of events was often missing. She states that she had been hospitalized in the late sixties and then not again until she became sick three or four years ago. She spent some time in a nursing home for rehabilitation after one of her hospitalizations. Although her recall of much of her medical history is at times poor, she is acutely aware of her arthritis because it has affected her ability to play the piano. Prior to referral to hospice, she remembers talking with her physician about the possibility of dialysis, but it was determined that she did not need to initiate that therapy. Her long-term physician made the referral to hospice for her. To her, hospice means a volunteer who reads to her and keeps her mind stimulated and visits from nice visitors.

She had been in hospice for 17 days at the time of her interview, and she was having few physical symptoms at the time except for occasional constipation, urine retention and headaches. However, for the past five months she had been seeing people that no one else in the household had been seeing. It did not distress her that she was seeing something that no one else was seeing and she knew it was not real. She stated, “Some of this I see, I call it a fantasy.” She was very angry with the people that she was

seeing. One of her second husband's relatives (sister or former sister-in-law) figured prominently in the visions. She felt that these people represented some unresolved anger over the way she was treated after the death of her husband. Although she did not say it directly, it is possible that the visions may have also represented Mrs. Proctor's anger at her husband during his lifetime and the financial issues that came to light after his death.

Her former students came to visit her in the nursing home and once surprised her by getting a group together to sing for her while she was there. Julia and another one of Mrs. Proctor's students made regular visits to see her at the facility and when she returned home. She returned home for a time, but it became increasingly difficult for her to care for herself and her dog and companion, "Lady Bird."

When Julia found out that Mrs. Proctor was having trouble caring for herself at home, she invited Mrs. Proctor to move in with her family. At the time of her interviews she had been living with Julia for 8 months. When she made the move she had to give up two things very important to her, her piano and Lady Bird. She states that giving up her piano and Lady Bird were the two hardest things about living with her illness. Julia did not have room for her dog and so Lady Bird was not able to move with her. Mrs. Proctor's goddaughter now takes care of Lady Bird and brings her to visit. Julia borrowed an electric keyboard from her mother so that Mrs. Proctor would still have her music with her in her new home.

Mrs. Proctor's students continue to provide emotional support to her while she is living with Julia. Her students sent flowers on Mother's day and two former students visited, prayed and worshipped with her at Julia's home. One of the students even took

up a small offering. She was very surprised and quite pleased with that. She has even chosen one of her students to play the music at her funeral.

Researcher reflections. Early into the first interview, I realized three things. First, she wanted to be able to share her history and have the words written down before she lost those memories. Second, her occupation as a teacher transcended a specific subject. She taught important life lessons using the medium of music. She also passed down the legacy of service from her grandmother and father. For her, teaching was not a job, but something she was called to do. Third, I realized that now I was one of her students, too.

She was in many ways a pioneer: a college-educated African American woman, one of the first African American teachers to teach in the schools in her county after integration and a singer who traveled in the Florida Panhandle and performed gospel music and then was featured with her trio on a fifteen-minute radio show each week in the late 40s. My visit provided her an opportunity for life review. She gained strength not only from the relationships in her life today, but also from being the granddaughter of a mid-wife and pastor's daughter.

Mr. Jackson's Story: A Joyful Life

This case study was chosen because it illustrates two significant themes. First, people living with a life-limiting illness rely on their family members to interact with the medical community, including researchers. The informed consent process in this context is initiated in connection with significant family members. Secondly, African Americans will participate in end of life research studies, even when they have physical limitations, when a researcher invests time to create a relationship with the participant and family.

Mr. Jackson was an 81-year-old widower living with his son and daughter in a rural community 15 miles to the east of the university. He was diagnosed with prostate cancer

and had been in the hospice program for 5 weeks at the time of his interview. He met me twice, once alone and once when his daughter was present. At the first visit to his home, I was met at the door by Mr. Jackson's son. He escorted me through the sun porch and into the living room. Mr. Jackson was sitting in his wheelchair that was placed facing the television set. He was wearing a ribbed tank top and a pair of pajama bottoms. The cut of his tank top emphasized how thin he was and made it easier for me to visualize his collarbones and the veins in his neck. I sat down to the right of Mr. Jackson, introduced myself and explained the purpose of the visit. Communication was difficult because Mr. Jackson spoke with a soft voice and was hard of hearing. He rarely made eye contact.

I explained the purpose of the study and what would happen if he agreed to participate in the study. He requested that I meet with his daughter before he would agree to be in the study. He also voiced a concern about confidentiality and did not want to have anything taped. He asked me to come back when his daughter, Betty was available.

I spoke with Betty and made arrangements to come out when she was at home five days later. This time Betty met me at the door and walked with me into the living room. We sat down on the couch and talked about the study. He had shared his concern about confidentiality with Betty and she wanted to make sure she understood what was being asked of him and how the information would be kept private. Once she was satisfied with the explanation of the study, she asked me to wait in the living room while she asked her father's permission for me to come into his bedroom to talk with him. He agreed to meet with me again.

Today he seemed a little weaker. He was lying in his hospital bed wearing pajama bottoms covered with red and black dots and a ribbed tank t-shirt. He had no sheets or blankets covering him and his concave abdomen could be seen through the pajama bottoms. The bed was covered with a white sheet and green and white bed pads. His room was rectangular and his bed was placed up against the left wall. Across from his bed and up against the right wall was a quad cane, bedside commode, folded up wheelchair and a small table (a small TV table) that was covered with medication bottles, a small white medication box and a various personal items.

His recumbent position made it even more difficult for me to hear him on this visit. On this visit I positioned my chair to the left side of bed facing him so we could make eye contact. Betty sat on the bed next to her father. I reviewed the purpose of the study with both of them. He repeated that he would like to talk with me but did not want to have anything taped. He was also wanted to know what type of medical information would be collected. After the initial explanation of the study, Betty would occasionally step out to tend to things in another room or to answer the phone.

Biographical sketch. Mr. Jackson was born and raised in the rural community where his interview had taken place. He left home for military service, first to Ft. Stewart, Georgia, and then overseas to Japan. He returned to his rural community in 1946 and has lived there ever since.

Illness journey. He was first diagnosed with prostate disease in 1999. It was hard to hear what he was saying, but he used hand gestures to demonstrate the difficulty the doctors had in passing a catheter and to simulate the blockage in the prostate that he said was “blocked up tight.” Apparently he had been ill for a while before he had been

referred to hospice. I asked him how he had gotten referred to hospice and he stated, "I don't know nothing about it." His daughter had set it up. He called Betty "his interpreter." She told me that she had initially called the American Cancer Society for financial assistance and was referred to hospice.

He was very weak and the informed consent portion consumed 45 minutes so the interview was short and focused on his biographical information, his family and the general evaluation of his life. He described his life as being wonderful because he had lived a long life and he was quite pleased that he had lived to be 81 years old. He attributed his wonderful life to a wonderful family, a joyful life and his personal belief in God. He stated that although he had not lived a life in the church, he believed that God had guided him and was responsible for him being here now. His belief has gotten stronger over time. The interview ended and Mr. Jackson and I made plans to meet the following week, but he was too weak to participate. The family did not permit any further contact due to his condition. He died a month after his last interview.

Researcher reflections. The interview was at first stressful for me because of the need to explain the study multiple times, communication challenges and note-taking in lieu of audiotaping the interview. When all of the informed consent process was completed and we began to talk, it was as if the sun had come out after a rainstorm. He began to grin and his joy started to pour out into the room and splashed on to me. I could not help laughing and soon he and his daughter were laughing, too.

At first, I could not tell that he was joking. He first started to tease me about taking notes. He did not want his interviews to be taped, but did permit me to take notes. I am sure I looked distressed as I was furiously trying to write down what he said. The

laughter loosened me up and allowed me to be present with him rather than focusing on my notes.

The interview was relatively short in duration due to his physical status, yet he was able to communicate the joy in his life, his love for his family and his personal belief in God that transcended a specific house of worship. Also during the course of the interview I got to see that he relied very heavily on his daughter, and for him his daughter was part of the informed consent process. I also wondered if he was testing me to make sure that I was someone who could be trusted with his stories.

Mr. King's Story: I'm Not Ready to Turn Loose

Mr. King's case study was chosen to illustrate variations in the experience of living with a life-limiting illness. His case study illustrates a trajectory of the advanced stages of a chronic illness, the desire to talk about death and dying issues, a personal relationship with God and a paradox between affirming God's omnipotence and pursuing aggressive treatment.

Mr. King was a 70-year-old man living with his niece in a rural community 30 miles north of the university. He was separated from his wife and he had one son. He was diagnosed with chronic obstructive pulmonary disease (COPD) and had been receiving care for over six years from the Veterans Administration's (VA) home care agency, but was not enrolled in hospice.

Biographical sketch. Mr. King was born in a small town near the gulf coast of central Florida. He and his family moved to the community where he is now living when he was 10 years old. Around the same time his father was killed at 33 years of age in a dispute with a girlfriend. It was not clear from the transcripts or my field notes whether the family move was as a consequence of his father's death.

He talked at length about his work in construction and the pleasure he got from seeing the results of his work in different places such as sidewalks, curbs and buildings. This work also provided him with the means to provide a home for his mother and sisters after the death of his stepfather when Mr. King was 17 years old. He had dreams of being a space scientist while growing up and had taken some tests that indicated he had above average intelligence. He graduated from high school but instead of going on to college he entered the military. He worked in a branch of the service that dealt with chemical, biological and radiological agents and was able to use his interest in science in that capacity.

When he left the service he returned home but did not pursue a college education. Instead, he went back to construction work to provide for his wife and son. When asked about the GI bill, he said that it was not set up for them at that time in the 1950s. He alluded to some of his disappointments but did not go into detail. He did become tearful while talking about the premature deaths of some of the men he grew up with in his community. He wondered how much some of things they were exposed to in the military contributed to their deaths. He also spoke about his loneliness because he was the only member of his family of origin that was still alive. He came to the conclusion that although everything had not worked out as he had planned, he had lived a good life, he still believed in God and stated, "I'm a winner."

Illness journey. Mr. King's nurse practitioner recommended him as a participant in the study. She described him as having end stage COPD because he had been hospitalized seven times in the last nine months. He stated that he has been hospitalized more times than that this year and is well known to the local ambulance crew.

He completed three interviews with me over a period of three weeks. During that time he did not report any visits to the emergency room, but within a week of his last interview he returned to the emergency room at the VA. All of the visits were done on his front porch. He described several times when he could not breathe, but he did not wear oxygen or appear short of breath during the interviews. All of his interviews were at least an hour in duration.

Two weeks before his first interview, he had been admitted to the surgical intensive care unit (SICU) after an episode of not being able to breathe and having chest pain at home. He was hospitalized for five days and it was determined that he did not have a myocardial infarction. On the second visit I asked Mr. King, "What do you think the increasing number of hospitalizations mean?" Mr. King described the changes in his body. At first he used terms such as, "Everything is wearing out, it's a progressive thing." He used a narrative to chronicle the events leading up to his most recent hospitalization. While telling the story he stated that he knew his illness was terminal. He based that on the deterioration of his veins and the fact that "high blood" and vascular disease lead to a stroke or heart attack. He made the following analogy to describe his experience of slow progressive deterioration of his body from his chronic illness:

Like some cars they go along and they just shut down and die, some of 'em go along clunk, clunk, bam, bam, up and down the road, that's the hard way, that's the, excuse me, hard way.

Mr. King is coming to terms with the advanced stage of his illness by acknowledging his physical changes and preparing a living will. He believes that his situation will get worse, but he would not think of taking the short way out and taking his own life. It appears that he has made a distinction between suicide and not being placed on life support. He stated that he has chosen not be placed on life support to prevent

hardship for his family, but he has some ambivalence about implications of the living will as evidenced by his use of emergency medical services (EMS) and the multiple hospitalizations over the past nine months. He stated, "The ways things happen is the order of things, but, I am not ready to turn loose and leave here."

Mr. King maintains a personal relationship with God that helps him with the challenges of his illness. He maintains a relationship with God by having a strong personal belief and communicating with Him. He says he does not need to see the evidence to know of God's presence, however there are times where he knows that God has made a difference, such as when he goes from feeling that his life is in disarray to feeling in control.

He maintains a relationship with God by communicating with Him. He uses talking, praying and meditating as synonyms for ways to reach God. He adds the stance of humility to his communication with God because he believes that humility is a "teaching word." When he is humble then God can reach him to provide support and guidance. Mr. King provided an example of how he used prayer to communicate with God during an episode of shortness of breath. A family member and the EMS staff told him later that he had passed out, but he remembers praying during the episode. An excerpt from his interview that describes prayer during the episode of shortness of breath is below:

I don't steady pray like that. I say well, you know, ...Jesus, you know I say, you know I believe in you everything right now, right now I can't pray but you know I trust you with my body.

Mr. King also talked about the importance of, in his words, "getting it together mentally." He stated, "Belief in God is a positive thought." His belief and

communication with God appear to help him to prepare for future events, to replace negative thoughts with positive thoughts and to restore order in his mind.

What made him distinct from other participants was that he was the only one to introduce the topic of what would occur after he died. He used a phrase called “the embarrassment of dying” to talk about loss of control and the vulnerability of being dead and not being able to present yourself with dignity. To illustrate this he told a story about the death of his stepfather. He was called home from work after the death and went in the bedroom to see him. He had died with one leg drawn and his mouth open. Mr. King was dismayed because neither his mother nor his sister appeared concerned about the dignity of this man. He took it upon himself to restore dignity by preparing his stepfather for the visit of other family members. He then concluded discussion of this topic by talking about what would be happening in his family after his death. He stated that after his death, “I’m not part of what’s mine or I’m not part of somebody’s life anymore”. He wondered what would happen to his possessions. “What would my son do with the house?” He did not believe that he could affect what would be happening after his death. He seemed to enjoy being able to speak the questions aloud.

Researchers reflections. He was very eager to participate in the study, and I had to slow him down to complete the informed consent process. We met for the interviews out on his front porch. The sounds of cars and people yelling out greetings and salutations can be heard on the tape. At one point he even pointed out his wife’s “old man.” They are separated, but not divorced and everyone is on friendly terms. I got the feeling that he was showing me off to his community.

The interviews with Mr. King were intellectually challenging because once we left the discussion of his illness he really wanted to dialogue with me about many issues related to death and dying at a very sophisticated level. First it felt as if I was talking with a philosopher and then it dawned on me that I had encountered a fellow seeker. I was trying to make sense of experiences with death and dying among a group of people and he is trying to make sense of his own life and death. I have access to statistics that document the relatively low life-expectancy of African American men; in contrast he had experienced the losses of his father, stepfather and his male contemporaries from the community. It felt as if he were hungry to share some of the thoughts that had been bottled in his head. Perhaps he did not have someone to talk with or maybe there was not someone who would discuss death and dying topics with him.

Mrs. Grace's Story: You Gotta Love God Without Wavering

Mrs. Grace's case study illustrates that religion and spirituality are the important concepts in the lives people living with a life-limiting illness. The language of religion and spirituality were used to reinterpret the physician's prognosis, to talk about healing and to search for the purpose of the illness in this case study.

Mrs. Grace is a 63-year-old woman who had been diagnosed with congestive heart failure (CHF) two months prior to her interviews. She had been enrolled in hospice for six weeks. When her social worker, Maggie Evans, was contacted to determine if Mrs. Grace would be a good person to approach about the study, she requested that I wait a month before calling Mrs. Grace because she had been reluctant to discuss death and dying issues with the hospice team. Maggie feared that participating in the study might be upsetting for Mrs. Grace. Maggie also requested that she be allowed to be present at the first interview to gain insight on how to approach these issues with her. I waited to

answer the question until after I had met Mrs. Grace. Creating a relationship with a participant can be delicate, especially when the topics are related to death and dying.

The first contact with Mrs. Grace was by phone. Her voice sounded clear over the phone during our conversation. I explained the purpose of the visit to her and she agreed to meet the next day. Mrs. Grace met me at the door and escorted me in to her home. She was dressed in a green, cotton, short-sleeved shirt with matching pants. A nasal cannula was visible in her nose and a long cord could be seen snaking past the couch and into another room. She was never in any distress during interviews and commented on the fact that she is relatively symptom free. The interview started in the living room and then moved to the small table in the kitchen.

Biographical sketch. Mrs. Grace has lived all of her life in a rural community to the west of the university. She married at 15 but is currently divorced from her husband. She proudly says that she has a close-knit family of nine children, 25 grandchildren and 10 great-grand children. She worked in her community as a manager of a convenience store and as a clerk for a gas company. Mrs. Grace has also been very active in her church where the congregation appreciates her cooking and her contributions to the church family. A pot could be heard simmering on the stove and intermittently she went to stir the contents during the interview.

Illness journey. Mrs. Grace had her first heart attack when she was 59-years-old. She had been having symptoms, but had ignored them until the morning she developed a fever and chills while getting ready to go into work. In the four years since her attack, she had been hospitalized 6 or 7 times, most recently in July. It was during this

hospitalization that the doctor talked to her and her family about her prognosis and made the referral to hospice.

All patients who are enrolled in a Medicare-certified hospice program must have two physicians (the patient's attending physician and the hospice medical director) certify that they have a life-expectancy of six months or less (NHPCO, 2003; Moore & McCullough, 2000). Mrs. Grace and her family heard the doctor say that her heart was not working properly and there was nothing more that could be done to repair the damage. The doctor asked her if she wanted to know how much time she had left and Mrs. Grace stated, "she did not want to hear that." She responded to the distress of her daughter and son-in-law by saying, "I'm gonna be alright because I know Jesus."

Mrs. Grace made her own evaluation of her prognosis. She felt that God had intervened and she will live longer than the doctor had in mind. When the doctor asked her if she would be offended if she was referred to hospice, she stated, "I wouldn't be offended because I don't care what hospice or her say, that I was not going anywhere until Jesus say so. 'Cause he has the last word'." She believes that God controls the doctors and only He can determine when she will die.

Religion and spirituality were very important to the life of Mrs. Grace. She had grown up in a religious home, but once she left home she did not live a Christian life until she returned to the church seven years ago. The presence of religion and spirituality can be seen in her personal relationship with God, the religious symbols she used in her search for meaning and the support provided to her by African American churches in her community when it was learned that she was seriously ill.

Mrs. Grace declared that she has a personal relationship with God. She communicates with God through solitary prayer and as a member of her prayer group at church. She uses prayer to make requests of God. For example, when she learned how ill she was, she asked God to “make me anew.” Asking God to “make me anew” seemed to be a request for healing. Healing was a frequent theme in her interviews. The quote below from one of her interviews talks about how God answered Mrs. Grace’s prayer for healing:

I said God is making me new all over. ‘Cause every piece of skin you see is new, every bit of it peeled, so he gave me new skin and everything.

Mrs. Grace searched for the meaning of her illness and came to the conclusion that God has work for her to do. Her purpose right now is to talk with young people in her family and community about the importance of living a Christian life and acknowledging the Lord as their Savior. She sees the illness as an opportunity to affirm her faith in God, too. She talked about reconciling the fact that while God had created this illness, He wasn’t trying to hurt her. It made her faith in God stronger.

Her church family has been a great source of support to her and Mrs. Grace acknowledges her blessings frequently throughout the interviews. Her pastor is a regular visitor to her home for spiritual and practical needs. He comes by on his way into town to take out her trash ever since he found her very short of breath while trying to get it out to the curb one day. One of things Mrs. Grace is most proud is that when it was learned that she was ill, the African American churches in her community got together and had a benefit program for her. She had an opportunity to see how much she was loved and the many lives that she had touched through her work in the community.

Mrs. Grace describes her reaction to the program in this excerpt:

...And it was so nice, I'm telling you, it's you look back and you see all these people and they came for you. And I kept getting up, going back hugging some people, you know, just, even my daughter that's crippled ... came. All my children.

Researcher reflections. Mrs. Grace's hospice social worker was concerned that participating in the study might be upsetting to her. However, she freely discussed death and dying issues with me in both of her interviews. I called Maggie to let her know that Mrs. Grace talked openly with me during the interviews. I told her about Mrs. Grace's demeanor in the interviews and the general topics that we talked about, but I did not reveal the specific content of the interviews. Because the study protocol included a method to contact the clinical team about any issues that might arise during the course of the interviews, I thought that sharing my description of her demeanor and the general topics were consistent with the protocol did not violate patient confidentiality or compromise my relationship with Mrs. Grace.

On every visit I saw family members leaving as I drove up to the home or there were people who just stopped by for a brief visit to see her. In her presence I experienced peace and serenity. I wondered what her home would be like on a Sunday or a holiday with all of her children and extended family gathering for one of her home cooked meals. In my mind I can hear the laughter and feel Mrs. Grace's love reaching out to embrace all of them. The presence of her family would be further confirmation that God will continue to answer her prayers.

Mr. Dell: I Just Don't Have Use Enough of My Body

There are many medications, treatments and assistive devices that can be used to control symptoms and manage physical limitations; however at some point physical deterioration cannot be controlled. Mr. Dell's case study illustrates how physical

symptoms and physical deterioration impact the experience of living with a life-limiting illness and a person's self-definition.

Mr. Dell was a 90-year-old man who had been diagnosed with kidney cancer and had been in the hospice program for five years at the time of his interviews. Whereas his nurse, Colleen, thought he would be a good candidate for the study, other team members did not feel that he was the best choice. The staff felt that his reluctance to discuss death and dying issues and his limited education might be a barrier to his participation in the study. Colleen talked with Mr. Dell at her next visit and he agreed to meet with me to hear more about the study.

Mr. Dell and his wife lived in a rural community 30 miles north of the university. Traveling there was a challenge because the road to their home was nearly impassable due to multiple potholes filled with water and at several points along the way the road was covered with soft white sand. Mrs. Dell had given me some landmarks to guide me so when I saw the mailbox on a pole with their name on it I knew their house was immediately across the street.

I walked up to the house and entered through a small porch. The front door was open and so I called out to them. Mr. and Mrs. Dell were sitting in a rectangular living room. She was on the couch and he was seated in a brown tweed chair that was covered with a multi-colored speckled afghan. I sat down in a small love seat directly across from Mrs. Dell and diagonally across from Mr. Dell. He was wearing a white shirt and a pair of pants. The room was lit only by sunlight coming in from the open front and back doors. I noticed a hospital bed covered with a navy blue blanket with green squares. Communication was difficult at first because he was hard of hearing, I was too far from

him and poor lighting made it hard for him to read my lips. The informed consent process improved when I moved closer to him, turned on a light in the dining area and he put on his glasses.

When I changed position I could see a field planted with large dark green plants that literally came up to the backdoor. The plants looked like corn to me. I worried for the first few minutes if a small animal was going run out of those plants and up into my lap!

I reviewed the study with Mr. Dell and his wife. He was able to state the purpose of the study and what I would be asking him to do. He restated both without hesitation and after he signed the consents forms we started the interview. Mrs. Dell was present for all of the interviews.

Biographical sketch. He was born and raised in a rural community approximately 40 miles north of the university and about 15 miles north of his current home. Although Mr. Dell has not worked on the land for a few years and the majority of the farm animals had been sold, he still defines himself as a farmer.

Owning his farm was a way for him to maintain his independence and autonomy in a segregated community. In contrast, many African American men of his generation worked as sharecroppers or on the land of other people. He supplemented the family income by working for others between growing seasons but he found the most satisfaction when he was farming his own land. I asked him, "What do you love about farming?" He stated, "It's not the money you make, it's just the privilege you have to do what you want to do, and how you want to do it."

He and Mrs. Dell did not have any biological children, but they did raise a son together. My field notes did not reveal if this child was related to one of their relatives or the events that led to his coming to live with them. He currently lives in Pennsylvania.

Illness journey. Mr. Dell's chronology of his illness journey was inconsistent because of his memory loss, however he is very clear that a stroke and the after effects from multiple surgeries were watershed events in his life. The stroke had affected his memory and decreased his energy. As a result of multiple surgeries, he was hard of hearing, had poor eyesight and trouble keeping his balance. He spoke passionately about the changes in his body, the unpredictable nature of his symptoms and the change in his self-image since the surgery and his stroke.

The surgeon told Mr. Dell prior to one of his surgeries that he would have problems with his memory, hearing and sight. Mr. Dell stated, "He told me those things was gonna happen and they most certainly did. That just wrecked me." His wife reminded him that there were things that he could do for himself, but that did little to appease him. His frustration over the loss of his physical body was a topic in all of the interviews. Although, he has symptoms such as abdominal pain, constipation and insomnia, he says that his loss of his ability to get dressed has been the most distressing because, "I just don't have use enough of my body."

Mr. Dell was surprised that after his surgeries he had trouble maintaining his balance. The loss of balance has required him to use a walker to move around the house. He describes his balance this way, "My balance is so bad, I, it's like somebody drunk. Staggerin'." The hospital bed that I saw when I first came was a recent arrival. It had been in the home for two or three weeks.

He is also distressed that he cannot predict when his symptoms will appear, the duration or when they will return. When he uses the pain medication ordered by his doctor, the pain is relieved, but the unpredictability is frustrating. He describes the unpredictability of his symptoms in the following excerpt, “Some mornings I’ll get out of bed, I feel I could get out there almost and do a day’s work and maybe in an hour’s time, it looks like I’ll be sick enough to die.”

We talked about the meaning of work to him during the last interview. Work had a practical and symbolic meaning to him. Work provided him the means to provide for his family and it also appears that work symbolized vitality and control over his destiny. He once defined himself by the work his “able body” could do. At this time his body has betrayed him.

Mr. Dell was once very active in his church as a deacon. Although he cannot get to church because of his physical limitations, members of the church come in to pray with Mrs. Dell and him. His belief in God provides a sense of comfort and the visits from his church family lift his spirits for a time, but then he becomes depressed about his situation again.

He talked about his death without prompting from me. He acknowledges the probability that he will die in the near future at a time determined by God, yet he is still hoping that God can create a miracle. Mr. Dell died three months later at a nursing home under the care of hospice.

Researcher reflections. The staff expressed doubt about his ability to be in the study. If I had not taken the chance to talk with him directly then I would have missed an opportunity to hear his perspective on living with a life-limiting illness. His third grade

education did not affect his ability to speak very candidly about his frustration with his body and the loss of his ability to work. Work provided him with the means to take care of his family and to be independent. I think that he had lost the means to define himself. I would have liked to have had further contact with him to see if was able to come to some resolution or create a new definition of himself that could incorporate his physical limitations. Mr. Dell was the second person that the clinical team members believed would be reluctant to discuss death and dying issues with me. He was very open and frank with me about the impact of his physical limitations on how he defined himself. Mr. Dell acknowledged his death, even in the presence of his wife. After I found out how long he had been in the program I became more curious. If he is reluctant to discuss death and dying issues after five years, when would he want to discuss them? I also wondered what was contributing to this reluctance?

Summary

The case studies present experiences from a rural elderly population that has been diagnosed with a life-limiting illness. Their worldview has been forged and tempered by factors in the cultural and social context that might influence living with life-limiting illness.

Sociocultural Context

Religion and spirituality. The largest cultural influence comes from religion and spirituality. The participants in this study talked about the importance of their religion and spiritual beliefs to their lives during a life-limiting illness. A personal relationship with a human God was very important because this relationship provided a safe place to share concerns and fears about aspects of the illness, especially the topics of the physician's prognosis and their own beliefs about death and healing. They described and

interpreted their experiences in the language, symbols and the music of religion and spirituality. Important concepts that emerged during the interviews about religion and spirituality were concepts such as, but not limited to, God's omniscience, personal faith, healing, overcoming adversity with God's support, traditional gospel music and Bible verses.

African American church. The African American church is a central fixture in the lives of many of the participants. It provided them with opportunities for leadership, connection with the community and a source of instrumental and emotional support. Even for participants who could not leave home, the church members came to the home for fellowship and prayer.

Experience with death and dying. The elderly population in this study has experienced the death of many family and friends, as would be expected given the age of the sample. For example, Mr. King and Mrs. Proctor are the last survivors from their family of origin. However, African Americans have a different experience with death and dying. African American men are estimated to have a life-expectancy of 68.3 years. The participants of the study have a first-hand knowledge of the limited life-expectancy of Black men. Mr. King spoke about the loss of his contemporaries, his father and his stepfather. When Mr. Jackson declared his pride about being 81, it has more impact when it is placed along side the limited life-expectancy of Black men. The participants know how precious life is.

Interaction with health care system. There have been many changes in the health care system during the life span of the participants. Forty years ago life extending technologies were in their infancy, the cause of death was related to an acute illness and

the hospice philosophy was almost unheard of in the U.S. Today, the health care system can provide multiple options for life-extending care, the cause of death is related to a chronic illness and the hospice philosophy has expanded to include a program of services to provide care to people who are dying.

The participants in the study have had multiple interactions with the health care system, especially with the physician, during the course of a life-limiting illness. The physician has also been identified as a gatekeeper in the health care system; for example, a person cannot receive services from a hospice or home health agency without a physician's orders. Moreover, to access the full services and financial benefits of hospice, two doctors must certify that the person has a life-expectancy of six months. In essence the physician must define the person as being terminally ill or having a limited life-expectancy.

The discussion of life-expectancy or prognosis was one of the major topics discussed in the interviews. The participants often countered or reinterpreted the conversation about their prognosis using religious language such as "God has the last say so" or "By his stripes I am healed."

Messages from the body. The participants were also receiving and interpreting messages from their bodies. The messages come from physical symptoms and symptom exacerbations. Most of the sample had few physical limitations, however, Mr. Dell's case study illustrated the challenges of living with physical symptoms and that a life-limiting illness can also be interpreted by looking at symptoms from the body. His case study also illustrates one of the themes introduced by the participants, the fear of being dependent on others. There were participants who were reluctant to talk about how they

would handle a future when they would have to depend on others for care (The sociocultural context and the themes illustrated by the case studies are summarized in table 4-A).

The research questions guiding this study were:

1. What is the basic social psychological problem shared by African Americans living with a life-limiting illness?
2. What is the basic psychological or sociological process used by people living with a life-limiting illness to manage that problem?

The problem they share is, “How do we affirm life given what we have experienced and the messages we are receiving now?” Affirming is defined in American Heritage Dictionary as: 1. To declare positively or firmly; maintain to be true. 2. To support or uphold the validity of; confirm. The word is derived from the Latin *adfirmare* that means to firm or strengthen (American Heritage, 2000). The case studies illustrate that African Americans are drawing upon religion and spirituality to cope with a life-limiting illness to solve the problem of “Affirming life.” The next chapter will discuss the strategies used by the participants to solve this problem.

Table 4-A The social cultural context and themes illustrated by the case studies.

Sociocultural context	Themes from the interview transcripts
African American Church	Social support Instrumental support Opportunity for leadership Connection with community
Religious and spiritual perspective	Religion and spirituality topics God's omnipotence Connection with God Prayer Healing
Interaction with the health care system	Physician's prognosis Medicare Hospice Benefit
Messages from the body	Pain Physical limitations Fear of dependence

CHAPTER 5 KEEPING FAITH

Basic Social Psychological Process: Keeping Faith

Faith is defined as a firm belief in something for which there is no proof, complete confidence, something that is believed with strong conviction (Agnes, 2003). Another use of the word is faith in a religious context where it connotes the traditional doctrines of a religion, belief and trust in and loyalty to God. This is also consistent with usage of the term in Roget's Thesaurus (Roget's Interactive Thesaurus, accessed 2003). Therefore, the use of the word faith goes beyond a religious context.

"Keeping Faith" brings to mind a sense of steadfastness that can restore order during a time of chaos or renew spirit. Barbara Jordan stated during the impeachment of Richard Nixon, "My faith in the constitution is whole, it is complete, it is total (Greene, 2002, track 25)." The timbre of her speech and the unwavering passion in her delivery gave life to her words. When the participants in this study talked about the strategies that were used to affirm life, the same resolve could be heard in their voices.

The participants in the study used the literary devices of metaphor, allusion and narrative to describe the process of "Keeping Faith." The metaphors and allusions were derived primarily from the Bible and religious music. Occasionally, two metaphors were combined to communicate an idea or a phrase was attributed to the Bible when there was no literal or metaphorical referent to support the usage. Metaphors also came from their

life experiences, such as metaphors from baseball, cars and their occupations. Narratives were used as a device to facilitate discussion about many aspects of living with life-limiting illness.

Connecting

The process of “keeping faith” is composed of three major concepts: connecting with family and community, connecting with God and connecting with Self. Connecting in this model is defined as the state of “being in relationship” with objects in the social world and is the concept that integrates the model. The participants are able to solve the problem of “Affirming Life” in relationships with objects in the social world.

Connecting with Family and Community

Participants were in relationship with their family members in the past, the present and the future. Relationships with ancestors, their parents and even a deceased spouse were important to them. The participants used stories to describe connections with ancestors who they believed to be the source of their own values. Mrs. Proctor’s story illustrated her connection with her ancestors and her pride in their accomplishments. One of her favorite Bible verses is from the Ten Commandments, “Honor thy father and thy mother (New King James Version).” This excerpt from the Ten Commandments is definitely about honoring the legacy of your ancestors and parents. Mrs. Proctor instilled this lesson in her students during four decades of teaching.

The connections with her students provided a safe place for her to live. Moreover, the relationships with her students created a place where she could be honored, cherished and acknowledged for her contributions to their lives. Julia assured that Mrs. Proctor’s soul was nourished by in-home fellowship, her music and visits from her dog, Lady Bird.

Passing the Torch

Connections with future were also important. A participant proudly talked about how she and her daughter were following in the footsteps of her mother, as they took on roles in the church leadership. She and her mother have the title mother of the church and her daughter is now a deaconess in training. Passing on a legacy to her daughter maintained continuity through three generations. Mrs. Grace, who was known to her community as a good cook, shared favorite recipes with one of her daughters and expressed delight that her daughter wanted to receive that gift from her.

Healing Relationships

Connection with others may also include the desire to heal relationships. One participant who is estranged from his children spoke about wanting to reconnect with his children. He shared during the interviews that his own anger and pride had created a barrier between him and his children. In the following passage he is expressing regret about his role as a father and seeking forgiveness from his children (and possibly from himself) for his absence from the lives of his children.

What's important to me right now? Believe it or not, the most important thing to me right now besides my health is my two ...kids in Sarasota. ... I enjoy being with them very much ...I didn't get a chance to grow up these kids up here and that's what they 're mad about. I wasn't there for them. When I wanted to be there for them I couldn't be there.

Connecting with Others

The participants had important relationships outside of the family that were maintained through the strategies of prayer, in home fellowship and music. Prayer was the most common strategy used to maintain connection with others the context. The participants reported praying for family and friends in a general way and also making specific requests to God on their behalf. They connect with others through solitary or

group prayer. Intercessory prayer during worship services, Bible study or prayer groups and in home fellowship provided a way for people who were housebound to stay connected to the church community and for the community to stay connected with their concerns.

Connecting with family and community during a life-limiting illness provides an opportunity to heal relationships, to reflect on contributions to family and community and to create a legacy. A social definition is created in relationship to community and family. The participant is comforted by the connections across the generations. These relationships are the foundation for the values and beliefs that they are using to sustain them while living with a life-limiting illness.

Connecting with God

Personal Relationship With God

A personal relationship with God was a concept that was introduced into all of the interviews by all of the participants. The majority of the participants used the word God when talking about their religious deity. One participant called this person a Supreme Being. God/Supreme being is consistently described with human characteristics. "Being in relationship" with God is the central concept in the process of "Keeping Faith." The participants describe the relationship with God as positive and egalitarian. The majority of the participants discussed this relationship in a religious context; however, being in relationship with God/Supreme being also transcended a specific religion or religious practice.

Strategies to Connect with God

Praying and talking were the primary strategies used for connecting with God. Praying and talking were both used to make specific requests on the behalf of family,

friends or themselves, and to affirm a belief in God. The participants used prayer in conjunction with affirming gratitude for God's presence in their lives. The only distinction between praying and talking as strategies to connect with God were the words the participants used to describe this activity. For example, when they described talking with God they would say phrases such as "I told God" or "Letting him know."

Participants dedicated time on a regular basis to connect with God such as morning prayer, bedtime prayer or with a prayer group. Two participants spoke about being in contact with God multiple times a day.

The concept of the personal relationship with God and strategies for connecting with God are illustrated by the quote below:

And I told God that I was willing to die, but I was not ready to die, and it seems to me what I was, getting to or referring to I was, either asleep or in a daze or something, I don't know. But, I hadn't been married long and I wanted to get more loving and closer and being more with my wife than I had been, to learn of each other. And I had communicated with God about the things that I was concerned about with my life and her life, so I just asked... talked to God as much as I wanted to, praise God, about that, that's why I said that I was not ready to die, but who was I to tell God such a thing as that. But as I understood the Bible, God wants you to talk with Him like your doing another man or another woman.

In the excerpt above it appeared that there might be a risk of being perceived as disobedient or unfaithful to reveal to God his ambivalence about dying. However, this participant acknowledges a personal trusting relationship with God and is able to share his ambivalence without fear of judgment.

Answers from God

The participants believed that connecting with God also involved receiving communication from God. The communication from God might be in the form of a tangible sign, such as pain relief, relief of emotional distress or unexpected financial gain. In contrast, communication from God might also manifest in an intangible form, such as

a feeling or a presence. One participant described receiving communication from God by using the phrase, “felt him through the spirit.”

Mrs. Grace was asked during one of her interviews if she was specifically praying for anything. She answered:

I just ask God to make me anew and my first prayer was if you made me, you got spare parts, so give me another (she tapped over her heart with a closed fist). I told my daughter at first I peeled, my skin peeled. And I said God is making me new all over, 'Cause every piece of skin you see is new, every bit of it peeled, so he gave me all new skin and everything.

Mrs. Grace is using images and symbols of renewal and creation in her request to God. She interprets her peeling skin as an answer to her prayer for renewal and she also acknowledges the role of God as creator. She does not use the word healed in this sentence, but it is possible that she believes that her peeling skin is the evidence that she has been healed.

Mr. King was asked how he knew he was talking to God. He answered:

...to step out into infinity well you see so there's no proof here to show me, there's no proof of me to put here to show me, but the proof is what I did, like you got yourself together, you know you was in disarray in your life and you got together...

The proof that he was talking to God came from going from a state of disarray to a state of order or control. The phrase “got yourself together” connotes going from a feeling of being scattered to a sense of integration or wholeness.

In God's Hands

The belief in God's omniscience and omnipotence were major concepts in the interviews because they appeared frequently in the transcripts. These concepts were commonly found in interviews that contained discussions about life-expectancy of the participants in hospice and homecare. The participants believed that only God knew

when they would die and His knowledge was superior to the medical knowledge of the doctors. God also had the power to heal and to create a miracle.

A participant told a story about how his prognosis was presented to him by his doctor. His son initiated the discussion at an office visit when he asked the doctor about his father's life-expectancy. In the quote below, the participant makes an argument supporting the supremacy of God and affirms God's omniscience. He is able to inspire hope for himself by framing this conversation in the concept of God's Omniscience.

...if I had known, if I had thought real quick, I wouldn't have let her answer him, but... he asked her, uh, what was my life-expectancy and she blurted out 6 months and uh, and I thought about it, ...that's something I really didn't want to hear, I didn't need to hear, 6 months ain't no long, long time, ...I don't know if he expected that answer or not. I'm aware of the fact that, that medicines are far more advanced now than they was a long time ago, they're more, more sure about things, but then that's still not, it's, it's, as far as being definite, you know, I don't, I just don't, because as he said, you know, not, as much advanced as medicine is and doctors and things they ain't still not God.

Taking It Out of God's Hands

Whereas the participants acknowledged God's omnipotence and omniscience, many participants had made decisions to stop treatment. Those decisions would appear to be in conflict with "leaving it in God's hands." Participants chose not to pursue surgical options, to decline chemotherapy and to complete advance directives that documented their decisions not to receive life-extending treatment. A hospice chaplain stated, "To some African Americans, choosing hospice might appear to be in conflict with the belief in God's omniscience." Did the participants in this study identify making a decision to stop or to decline further treatment as being in conflict with the belief in God's omniscience and omnipotence? If so, how do they make sense of this?

The participants made a distinction between allowing the process of a natural death to occur and the intention of ending a life. For example, Mr. King and another

participant introduced the topic of suicide during the interviews. They both stated that they would not choose the option of suicide.

Three participants introduced the concept of conflict between believing in God's omnipotence and making end of life decisions such as continuing to pursue aggressive treatment, choosing hospice, and declining chemotherapy. Data analysis identified three strategies used to ease the tension generated by the paradox and to create a space for the contradictions to rest side by side in the experience of living with a life-limiting illness.

Working Through the Paradox

Holding on. Mr. King was interviewed when he had been in the VAPHC program for 6 years. The number of hospitalizations for shortness of breath and chest pain had increased over the nine months prior to the interview. Mr. King talked about the paradox between acknowledging God's divine plan and continuing with aggressive treatment. The paradox was handled with the strategy of "holding on." He completed a living will that stated that he did not want to be on life support, what he called "being put on machines." However, he continued to use the EMS system, the emergency room in his local community and the intensive care unit at the VA hospital.

He acknowledged that although there is a divine plan, he was not ready to "let go." Maintaining control and dignity was very important to Mr. King. The phrase "let go" could be a euphemism for death, but in his case letting go also signified the loss of control and dignity similar to what he witnessed when he was seventeen after the death of his stepfather. "Holding on" is a strategy that provides comfort and sense of control to Mr. King.

Compromising. Mrs. Grace was interviewed within 6 weeks of her admission to hospice. Mrs. Grace justified her decision to accept the referral to hospice by

compromising. Each side makes a concession to reach a settlement in a compromise.

Mrs. Grace enrolled in hospice, but she told the doctor, in essence, “I’m not dying.” She believed that God’s intervention had healed her. Whereas she agreed to have access to the financial benefits of the Medicare Hospice Benefit (MHB), she would not give up the belief that God had healed her or define herself as dying.

Mrs. Grace used Job, a character from the Bible, to illustrate the importance of patience and her unwavering in faith in God.

You’ve heard of Job in the Bible, you know, lost his wife, his children, he was a rich man. He lost everything. But he would not curse his God and... and so, I like to pattern my life after Job. I’m not a rich man. But I’m not gonna deny God on no terms. Nothing or nobody. ‘Cause I know he’s Almighty and uh, and just like Job, I’ll get it all back.’

The character of Job has lost material goods, but kept his belief in God in spite of many challenges, including the loss of his family. The parable in the Bible goes to great lengths to describe his material possessions and as a reward for his faith he received a greater number of possessions than he had started with at the beginning of the story. She equates being in hospice and defining herself as dying with denying her belief in God. Therefore, she handled this tension by making a compromise.

Weighing costs and benefits. Another participant had been in the hospice program for a year at the time of her interviews and just like Mrs. Grace, she embraced her healing and justified receiving hospice services because of the financial benefits of the MHB. She described her illness journey using very sophisticated medical language, however, she expressed doubt about the doctor’s definition of her illness because it was in direct opposition to the belief that she had been healed. She was offered palliative radiation therapy and chemotherapy for treatment of her lung cancer when she had been

in hospice for four months. She agreed to accept the radiation therapy, but not the chemotherapy.

She used a narrative to describe the information she used while “weighing the costs and benefits” of initiating chemotherapy. She told a story about how chemotherapy had affected a friend: she lost weight, became bald and couldn’t eat. Her friend was ultimately confined to bed and required assistance with all of her needs. She described her friend in the excerpt below:

She stayed in the bed all day, every day. So, so what’s this living? Now, the way I am now, I’m fine. Sure I want to live. But if I live where I just got to lay there, people got to wait on me hand and foot, to feed me, ... (clears throat). I don’t want to be a burden on nobody.

She wants to live, but not at the cost of her independence or being perceived as a burden. She also communicates her own definition of quality of life. She resolved the tension in her paradox by “weighing the costs and benefits.”

The personal intimate relationship with God provides a foundation for participants’ belief in God’s omnipotence and the possibility of healing. The belief in God’s omniscience facilitates the discussion of their limited prognosis within their own belief system and provides them with hope. Participants in the current study resisted the concept of the physician as prognosticator and reinterpreted the prognosis conversation in the language of religion and spirituality. In this language God is the prognosticator and reliance on God’s omniscience puts the participant in control of this aspect of living with a terminal illness, places the determination of the time of their death in the hands of a trusted, benevolent God/Supreme being and affirms their relationship with God.

Healing is a common theme that was introduced by the participants to describe physical healing, for example healing of a wound or resolution of a physical illness.

Additionally, healing was introduced in the narratives about discussions related to a person's prognosis. One participant used healing when he discussed the possibility that God would heal a person by helping them to overcome worldly temptations. Metaphors such as a "rehaul job" or "making me anew" were also used.

Healing was seen as a gift from God and interpreted by a few of the participants as a reward for unwavering faith and living a Christian life. In the words of the participants, only God had the power to heal. Healing is also a metaphor for the theme of resurrection. Acknowledging mortality and hoping for healing is not a contradiction, nor does it reflect denial about the course of their illnesses. The Bible contains many references to the death and resurrection of Jesus. Death and healing (resurrection) are not opposites but part of the same cycle. The possibility of being healed by God provides hope and affirms trust in God's omnipotence.

Searching for Meaning

The participants wanted to attribute meaning to the cause of the illness, the purpose of the illness and purpose of their suffering. This search was done in relationship with God and through the use of religious metaphors and characters.

Mrs. Grace stated, "Although God allowed her illness, he did not cause it." God was seen as a source of blessings, unconditional love and abundance, whereas the Devil was identified as the cause of illness and symptom exacerbation. Participants also used their relationship with God to question the purpose of the illness in their lives and to question the purpose of their suffering.

The purpose of the illness in their lives was to continue to be of service to their families and community and to share the word of God. It was common for some of the older men to question why they had lived to be 80 years of age and older when many of

their contemporaries had not lived as long. The only answer they provided was that it was God's will for them to be alive.

Meaning of Suffering

One of the most poignant conversations that the participants have is when a person confronts God with questions about the meaning of suffering. This is really a time when faith and the relationship with God are tested. One of the participants describes a conversation with God where he questioned the meaning of his suffering.

... woke up at night, got out of my bed got on my knees and prayed and talked to the Lord and told Him how I feel felt and why and asked Him why I'm like this. Is this a punishment or do I supposed to suffer like this? And uh, and then I talked to Him, asked Him questions, I say I know people ... out there they've done worse things than I ever thought about doing. And they living and going on with good health and strength. Why I have to be like this? Okay?

Religious Metaphors

Another participant told of seeing a vision with three biblical characters just before he was discharged from the hospital and referred to hospice. He was searching for meaning in their presence. He had talked with God and expressed ambivalence about his death. He thought the presence of Peter, James and John might have been a symbol of his death. An excerpt from his interview appears below:

Well, I had thought about it, but I had been thinking all the time of praying to God asking for His blessings. And it seems to me as if I seen Peter, James, and John standing, he was, John was at the foot of my bed and he had a cane and a Bible or a book or something, a scroll in his hand. And it seemed like to me that he said it is finished. ... And I thought that was death. But I wasn't uneasy, I wasn't afraid or nothing. And I told God that I was willing to die, but I was not ready to die...

This passage is actually a mixture of images from two books in the Bible that present the death of Jesus. The characters Peter, James and John are three of Jesus' disciples who were present for an event referred to as the transfiguration

(Matthew 17:1-9). During the transfiguration God acknowledged Jesus as his son and Jesus foretold of his death and resurrection.

The phrase “it is finished” is from the Book of John (19:30). According to this verse in the Bible, “it is finished” are the last words that Jesus said before he died after being crucified. The full statement is:

So when Jesus received the sour wine, He said, “It is finished!” And bowing his head, He gave up his spirit.

Connecting with Self

Affirming Thoughts and Speech: “It is a Mind Thing”

Connecting with Self is a concept that encompasses strategies used to manage the mind, be in relationship with the changing physical body and a personal search for meaning. The mind is a concept that was presented by the participants as if it had a physical form. The participants talked about how they “don’t think about their illness” and commonly they use phrases such as “I don’t have no thoughts about it”, “Once you put your mind to it” and “I don’t dwell on the illness.” Those phrases connote not focusing attention on the illness (Agnes, 2003). The mind is seen as an object that needs to be controlled or harnessed.

The participants also talk about the concept of the mind, using phrases, such as “in your mind”, “on your mind” and “keeping it out of your mind.” In these phrases the mind is a container or vessel that can be filled or emptied of thoughts about aspects of the illness. All of the participants discuss the use of intentional cognitive strategies to manage negative thoughts or anxiety about the troubling aspects of the experience of

living with a life-limiting illness. Mr. King called it "getting it together mentally." Therefore, the goals of cognitive strategies used are to control what the mind focuses on and the content that fills the mind.

Managing the mind. Managing the mind is a strategy to manage thoughts about unpleasant aspects of the illness such as fear of being dependent, loss of control after death or financial concerns, so that the person has the energy to focus on handling important aspects of living with illness. Mr. King used a baseball analogy to discuss how he "got it together mentally." He stated that managing his mind was analogous to preparing for a tough pitch. To be effective in the game of baseball, a player must have physical and mental skills. The mental preparation for a tough pitch requires that the player remove thoughts from the mind that may prevent the athlete from staying mentally focused on the pitch. If focus is lost, the player might not be able to make adjustments such as altering the stance or the swing to increase the possibility of hitting the baseball.

Preparing for the tough pitch while living with a life-limiting illness requires staying focused on positive thoughts so that you have the energy to prepare for the challenges ahead, such as symptom exacerbation and physical deterioration. Another participant stated, "We in the stages now...that things will get better if you decide to make it better." He described managing the mind as a personal strategy in palliative care.

Affirming and Denying

Kubler-Ross (1969) described denial as one of the stages of coming to terms with a terminal diagnosis. Denial in this study was described as a way to pretend that the disease did not exist. However, in the people in the present study, their denial manifests itself differently. They talk about their experience of living with their illnesses, such as acknowledgment of their mortality, personal losses and the impact of physical changes on

their lives. Denials remove negative thoughts or aspects of the illness that may cause worry or anxiety from the thoughts of participants so that the participant can replace them with positive thoughts (affirmations) from religious and spiritual beliefs that may bring comfort and release of worry (Roach, 2003; Gawain, 1995; Samuels and Rockwood-Lane, 2000).

Sources of Affirmations

Quotes from the Bible. Biblical allusions are a source of powerful affirmations. One participant used denial and affirmation together when talking about reading about her cancer. She denied that she has cancer and affirmed that she has been healed. She used a biblical reference, “By his stripes I am healed.” This biblical reference also alludes to the crucifixion of Jesus and it is found in Isaiah 53:5. The passage affirms that because of the sacrifice that Jesus made, his followers have been healed. Healing in this passage appears to connote the concept of life or rebirth:

Now, it may not bother me now but at first I couldn’t read this here talking about the cancer and I just rather not ... I don’t know where I was at but it just brought tears to my eyes. ... I ain’t got no cancer that what the doctor say, Jesus said about his stripes I am healed and that’s what I believe.

She is not stating literally that she does not have cancer. She is emptying her mind, “the vessel,” of the image that cancer represents to her, of fear, anxiety and the possibility that the cancer could lead to her death. Her mind is then filled with a positive image of healing that was given to her as a result of the sacrifice of Jesus.

Another participant had the phrase “no fear” on the front license plate of his car.

When he was asked about the license plate he stated that “no fear” was found in the 23rd Psalm:

That's No Fear, no, I'm not afraid of anything. I'm not afraid to participate, I'm not afraid to say things, afraid to go places, everything, No fear.... When you put all that stuff together and look it up and see what it means, No Fear, that mean a lots.

"No fear" is found in Psalm 23:4. This verse starts with "Yea though I walk through the valley of the shadow of death, I will fear no evil for You are with me." This stanza is a powerful passage that affirms the omnipresence of God. This participant used the phrase as an affirmation and a source of comfort that he carried with him when he traveled any where in his car.

Spiritual music. Traditional gospel music is another source of affirmations. Mrs. Proctor talked about two songs: "Nobody Knows the Trouble I've Seen" and "It Is Well with My Soul." Both songs illustrate a personal intimate relationship with God that provides comfort during times of sorrow and of emotional distress. "It Is Well with My Soul" extends this theme to declare that God is present at all times. The last two lines from the first stanza of "It is Well with My Soul" are especially powerful: "Whatever my lot Thou hast taught me to say, It is well, it is well, with my soul." Both of these songs contain metaphorical and direct allusions to the death; however, death is celebrated as an opportunity to connect with Jesus and others who have died in "Nobody Knows the Trouble I've Seen." "It Is Well with My Soul" provides comfort because this spiritual affirms that God will be present for support and guidance in all situations.

The participants talked about possible consequences or outcomes from the use of affirming thoughts and speech. Failing to manage the mind or to use affirmations might lead to more hardship, lower morale, "allow the devil to enter your mind" or hasten death. Positive consequences of managing the mind and controlling the thoughts that fill the mind are an extended life span, self-motivation and a renewed spirit. One participant

described the positive outcome of managing the mind. He describes this positive outcome using words synonymous with rebirth and a new life for the spirit:

The more, best you can put that away from you and not think about it, the better off you is, it's created me a new clean heart and a renewed right spirit within me.

Reaching within. Prayer allows the participants to connect with Self by drawing forth their own inner resources during the life-limiting illness. Prayer was used to manage pain, dyspnea and insomnia. The participants described using prayer as an adjunct to pharmacological symptom management and at times it was the only intervention used to relieve pain and insomnia.

Personal Search for Meaning

Earlier in this chapter the concept of searching for meaning was discussed. The participants were searching in the context of the relationship with God, such as the cause of the illness, the purpose that the illness served in their life and for the meaning of suffering. However, the participants have a search for meaning that is accomplished in relationship with Self. The connections with family/community and God will facilitate this, but at some point this search for meaning can only be accomplished by the person living with a life-limiting illness. A person must determine the criteria used to evaluate quality of life and to define a meaningful existence (Frankl, 1985).

This work is done primarily in relationship with messages that are being received from the physical body, such as increasing symptom burden (symptom exacerbation, new symptoms) and the presence of physical limitations such as difficulty with ambulation, requiring assistance with bathing and decreased stamina.

Symptom management is the hallmark of quality end of life care. Clinical staff are skilled at patient assessment and the identification of assistive devices that will

compensate for physical limitations. However, the body will deteriorate during the course of a life-limiting illness. The changes may occur in a slow downward trajectory or in a trajectory characterized by periods of physical deterioration followed by stable periods of little deterioration. The symptoms can be managed and for the most part controlled to the patient's satisfaction; however, as death approaches the physical deterioration cannot be stopped. A person living with a life-limiting illness comes face to face with existential issues.

Creating Meaning: What If My Healing Is Not Physical?

Mr. Dell's case study illustrated how physical symptoms and physical deterioration impact the experience of living with a life-limiting illness. Other participants added more dimensions to this topic. For example, the topics related to the loss of independence, loss of control, loss of dignity and the fear of being a burden often accompanied discussion about physical deterioration. Although many participants discussed these topics, two participants were very articulate about the strategies used to manage the fear of the loss of independence, loss of control and being perceived as a burden. These two participants (a man and a woman) had some characteristics in common: a one-year length of stay in hospice program at the time of their interviews, independence in all aspects of their care and satisfaction with physical symptom management. In contrast to the experience of Mr. Dell, the physical symptoms and physical limitations of these two participants' were not a focal point of the interviews.

These two participants used multiple affirmations that encouraged physical activity and the belief in an inner motivation throughout the interviews. One of these participants used an affirmation that he attributed to the Bible, "The Lord said you make one step and I'll make two." The researcher sought consultation from the hospice chaplain to identify

the Bible verse that is the source of this allusion. The chaplain shared that this affirmation is commonly attributed to the Bible, but there is no literal or metaphorical source for this aphorism. An excerpt from his interview is included below:

I never have stopped. Like I always said long as you got the willpower you'll live. When you lose trust in yourself you can just kiss it goodbye.

He is declaring that staying active and having a strong inner drive will keep him alive. The phrase "losing trust in yourself" is a way of expressing his fear of about the loss of control and independence. He uses the phrase "you can just kiss it goodbye" as a euphemism for death. Given that he is in hospice, this euphemism could refer to a physical death, but it is possible that the death he is speaking of is a metaphorical death of his identity as an active and vital man. The researcher asked him to talk about his life when he is not as active as he was at the time of the interview. He did not want talk about that possibility.

The second participant spoke about the same inner drive that she calls "that wanna do." She used a narrative about her parents to illustrate the source of her belief in independence, hard work and the internal motivating drive. The same narrative also told how she passed on those beliefs to her children. Her family valued education, but independence and the inner drive were held in higher esteem. She stayed very active with her church activities and family commitments. She was very emphatic that she wanted to stay independent. This quote is from her last interview:

I don't like to depend on nobody for nothing, do it yourself. Something to be done, don't wait for nobody to do it, go on and do it.

This passage describes her fear of being vulnerable and of losing of control if she has to depend on others. If she were to depend on others, two things would be required: a new definition of herself and the reconsideration of her family values. She talked about

her fear of being a burden. Her last interview ended with the researcher asking her about her definition of being a burden. Tears could be seen welling up in her eyes and the taping of the interview was stopped. This participant was also one of the people who believed that she had been healed. Furthermore, she had multiple versions of one of the symbols of the resurrection, the rooster, prominently displayed in all of the rooms in her home and on the top of the doorbell on the front porch.

This interview generated many questions during data analysis: What will she do if it appears that her healing on earth may not manifest itself as a physical healing? How will she resolve the conflict between the family values of independence and being active when she is dependent on others? Staying active, using affirmations and drawing on an internal motivation are strategies that appear to maintain an affirming self-definition and provide insight into the criteria used to define a meaningful life. However, what is missing are strategies used to create a new self-definition when the body continues to change throughout the course of the life-limiting illness.

Summary

The purpose of this study was to develop a conceptual framework that would synthesize the experience of African Americans living with a life-limiting illness. The basic social problem that the participants in the study shared was “Affirming Life” and the basic social psychological process that they used to solve the problem was called “Keeping Faith.” This process was comprised of three concepts: Connecting with family and community, Connecting with God and Connecting with Self. Connecting (being in relationship) unified the concepts because it is through the connections to objects in the social world that the participants in the study defined themselves, found comfort and

created meaning while living with a life-limiting illness. The central relationship in this process is the relationship with God/Supreme being.

Religion and Spirituality

Religion and spirituality provided the foundation for the process of “Keeping Faith.” The influence of religion and spirituality could be seen in the language used to express spiritual concerns, the importance of a relationship with God and the belief in God’s omnipotence. Prayer was a strategy that led to multiple outcomes such as, maintaining connections with family, community and God; requests made for family, friends and self and participants being able to access inner resources.

Religion provided the language and symbols that were used to express spiritual concerns such as a personal intimate relationship with a higher power, connections to the past, present and the future and the meaning of suffering. The relationship with God was the source of great comfort and at times it was the source of great discomfort. For example, the participants identified a paradox between affirming God’s omnipotence and decisions made to stop treatment or initiate hospice care. This paradox was managed through the strategies of “hanging on,” compromising and weighing the costs and the benefits.

Comfort

Comfort manifested in diverse ways such as the physical symptom relief, a feeling of safety, a sense of control, release of tension, hope and spiritual renewal. “Keeping Faith” in the context of living with a life-limiting illness required interpreting the language of the medical profession into words and symbols that provide comfort

when facing issues that may conflict with personal beliefs. “Keeping Faith” in the context of a life-limiting illness may also require a new self-definition and reinterpretation of the criteria by which life is defined as meaningful.

Communication About End of Life Issues

Communication about the experience of living with a life-limiting illness is often done using metaphorical language and the creation of narratives to express ineffable concepts, such as hope, healing, fear and comfort. Healing can be used as a metaphor for renewal and resurrection in a spiritual sense as well as to symbolize healing of the physical body.

CHAPTER 6 DISCUSSION AND IMPLICATIONS

Religion and Spirituality

Integration of Religion and Spirituality

Religion and spirituality provide images of hope, comfort and solace while living with a life-limiting illness. Hall (1997) wrote that it was common for people to use language from a specific religious perspective to talk about spiritual concerns. Religion and spirituality have been described as separate concepts in the nursing literature (Eblen, 1992; McGrath, 2003). However, rigid distinctions and typologies that are commonly used in scholarly papers or journal articles do not accurately reflect the integration of religion and spirituality that was identified in this study and in other descriptions of African American religion and spirituality (Newlin, Knafl & Melkus, 2002).

The participants in the current study used the language of religion to express spiritual concerns, such as maintaining a personal relationship with a higher power, death and dying issues, the search for meaning and purpose in life. Barrett (1995) suggested that the foundation for the integration of religion and spirituality in the lives of African Americans is the traditional African worldview of continuity and wholeness rather than the Cartesian duality that is found in the United States.

Relationship as a Spiritual Concept

Burkhardt (1994) wrote that being in relationship is a spiritual concept that encompasses relationships with God, other people, Self and nature. Burkhardt asserted that the spiritual concept of relationship also considers relationships that are in need of

repair. Relationships that require healing are just as important to the concept of spirituality as the relationships that are considered positive and affirming.

The participants in the current study experienced spirituality in relationship with God/Supreme being, family, community and Self. The central relationship in this process of “Keeping Faith” is the relationship with God/Supreme being.

The importance of a relationship with a higher power was also seen in other studies, such as, spiritual narratives of elderly African American women, descriptions of spirituality by women from Appalachia, in an ethnography of a fundamentalist African American congregation in the urban Northwest, in the caregivers of African American adults with HIV/AIDS and as a component of African American spirituality. In these studies a personal relationship with God increased self-esteem was a source of optimism over adversity and provided love and affection (Abrums, 1995; Abrums, 2000; Black, 1999; Boyle, Ferrell, Hodnicki & Miller, 1997; Burkhardt, 1994; Engel et al., 1998; Newlin et al., 2002).

Connecting with Prayer

In the current study, prayer was identified as an important strategy used during a life-limiting illness to connect with God, Self and others. Prayer also was used as an intervention to manage pain, insomnia and dyspnea. The use of prayer is seen frequently in the literature as a method to connect with God, as a spiritual health care modality, as a strategy to initiate healing and as a personal expression of religious experience (Abrums, 1995; Boyle et al., 1997; Abrums, 2000; Dunn & Horgas, 2000; McGrath, 2003).

Abrums (1995) completed an ethnography that focused on the lives of women in an African American church in the Northwest. The sample was comprised of elderly people who were originally from rural communities in Louisiana and Georgia, similar to the

rural population in the current study. Members of this congregation coped with all aspects of illness, including death, by encouraging members to take action through prayer. The pastor called this “Operation Pray.”

The members used petitionary and intercessory prayer to provide support to the congregation. They prayed to God and made specific requests, but they deferred to God’s will by concluding the prayer with, “as you see fit.” Using “as you see fit” placed the request in God’s hands. The healing force of prayer and its power to change things were reinforced by the use of intercessory prayer for members of the congregation who were home bound. Prayer allowed those present in the church and those who were homebound to experience the spirit at the same time (Abrums, 1995).

Spring (2002) identified the role of prayer as a method to relieve pain in adults with many types of diseases, but there was no indication that any of the participants in the study were diagnosed with an illness with a limited life-expectancy. Prayer was used as the only intervention for pain or as an adjunct to pharmacological and non-pharmacological interventions. This is consistent with what was found in the current study. Spring also presented the concept of narrative as a strategy to create meaning during an illness.

Comfort

Comfort was a major concept in the current study. In the literature review the concept of comfort was presented as a broader concept that not only incorporated relief of physical symptoms, but also included concepts such as integration, experience of being a part of or related to others in the social world, safety and sense of being in control (Arruda et al., 1992; Morse et al., 1995; Rasmussen et al., 2000).

Participants in the present study found comfort in relationship with family, community, God and Self. Comfort was identified as the outcome of praying, using affirmations from the Bible and traditional gospel music, managing the mind and staying active. The comparison of findings from this study with the literature validates that comfort is a subjective, multidimensional concept.

The current study presented specific cognitive strategies that the participants used to provide comfort. The concept of managing the mind or using affirmations and denials to control the content in the mind was not present in the hospice and palliative care literature. Research studies focused on symptom management with some focus on psychological symptoms but did not present cognitive strategies used to provide comfort to people who are living with a life-limiting illness. Dunn and Horgas (2000) suggested that the use of prayer by older adults could be identified as a cognitive strategy used in self-care; however the sample included in the study was not diagnosed with life-limiting illnesses.

Healing and Life-limiting Illness: Denial or Comfort

Healing was a concept that was presented in the current study. The concept was used to connote physical and metaphorical healing. Lambrindou (2000) presented the story of Samira, an African American woman, who was enrolled in a hospice program in Pennsylvania. Her belief in healing created tension with the hospice team because the hospice staff interpreted her belief in healing and pursuit of life-extending treatment as being inconsistent with the hospice philosophy. They did not realize that the belief in healing was used by Samira to inspire hope and did not indicate that she did not understand her illness and prognosis. The staff's lack of understanding about this important source of hope for Samira created distress for the patient when she needed

comfort, support and understanding. This case study validates the importance of identifying how African Americans are using the concept of healing. Is it being used metaphorically to express a belief in spiritual renewal or to inspire hope? The concept of healing in the current study was used to provide comfort in the face of being confronted with their prognoses by the physicians. Declaring a belief in healing also provided participants with an opportunity to affirm their relationship with God/Supreme Being.

People living with a life-limiting illness should be allowed to make their own journey. To paraphrase Lorde (1980), integrating a life-limiting illness into the totality of a life (as defined by the patient) does not happen in one day. All sources of comfort should be acknowledged and honored.

Jesus as a healer. The participants in this study identified God as the person who provided healing. Healing was seen as a gift from God and interpreted by a few of the participants as a reward for unwavering faith and living a Christian life. Kinsley (1996) explored the role of Jesus as a healer in the Bible. Some religious traditions use Jesus and God interchangeably, whereas other traditions identify Jesus as the Son of God. One of Jesus' main roles in the Bible was as a healer.

Kinsley estimates that 20% of the gospels contain discussion of His healing or the consequences of the healing. Healing was not limited to physical healing but also included a positive change in thoughts and belief and Jesus' forgiveness for sins. The Bible documents forty-one healing episodes and there is the possibility that there were hundreds more that could be directly attributed to Jesus.

Jesus healed unconditionally by virtue of his spiritual power or authority. The main modality used in healing was spontaneous touch, but Kinsley suggested His healing

manifested through his charismatic personality and presence. This interpretation of Jesus as healer also indicated that the healings were used to demonstrate Jesus' spiritual mission because healing was placed in the context of tension or a struggle between opposing forces.

The participants in the current study focused on managing their thoughts and controlling the content that filled the mind. Kinsley's interpretation that an outcome of healing could be a positive change in a person's thoughts underscores the importance of the cognitive strategies of managing the mind and the use of affirmations to provide comfort while living with a life-limiting illness.

Beyond Symptom Management

Symptom management is the hallmark of effective end of life care; however symptom management cannot stop physical deterioration and the need to modify the social environment to help a person with a life-limiting illness to cope with physical limitations. The participants in the current study were coming to terms with the impact of physical limitations on their lives. Mr. Dell's poignant descriptions illustrated the difficulty in creating meaning when you have identified yourself in relationship to your body and that body is slowly deteriorating. Byock (1996) identified the acceptance of dependency as a developmental landmark during a life-limiting illness, but other authors have suggested that it may be a difficult landmark to reach.

The American Association for Retired People and the Carolinas Center for Hospice and End of Life Care commissioned a study about end of life issues. One of the findings of interest was that 72% of the African Americans who completed the survey feared total physical dependency on others more than they feared death (AARP Carolinas, 2003). Moreover, physical symptoms and limitations may symbolize disease progression. The

actual physical limitations may be overshadowed by the image that the changes symbolize to the person with a life-limiting illness, namely dependence, loss of control and ultimately death (AARP Carolinas, 2003; Flanagan & Holmes, 1999).

Theoretical Models

Developmental landmarks. Some of the concepts in this study are consistent with the developmental landmarks suggested by Byock (1996) and theme of continuity found in Leichentritt and Rettig (2000). The participants in the current study were able to talk about plans to assure the family legacy, to maintain connections with the past, to seek forgiveness and to acknowledge themselves for their contributions to their family and communities.

Social definition. Glaser and Strauss (1965) explored the concept of social definition in a grounded theory study of dying within the structure of the hospital. Although the experiences of patients were presented, the focus of the study was on the criteria used by the nursing and medical staff to determine if a person was dying and the strategies used within the hospital structure to control the information and to manage the environment of care.

The concept of social definition was also important in the current study. Participants in the current study resisted the physician's definition that they were dying and reinterpreted the definition in the language of religion and spirituality. Abrums (2000) identified the same reinterpretation. The author found that the reinterpretation was not simply a reaction to the medical system, but it affirmed a belief in God and placed control in the hands of the participants and their benevolent God.

Another distinction that has not been explored fully in the current study is that the physician's certification of a life-limiting illness is directly linked with the patient's

ability to access services and payment for the hospice services under the Medicare Hospice Benefit. Essentially a person must be defined as having a life-expectancy of six months or less to be able to access this benefit. The traditional Medicare benefit does not cover the full payment for medications, equipment and supplies for the primary diagnosis. Unless the patient has a supplementary insurance coverage, the patient is billed a co-pay for equipment and at this time there is no Medicare coverage for prescriptions.

Two participants used the strategy of compromising to be able to access hospice services and the financial benefits without giving up their belief in healing or defining themselves as terminally ill. Other participants may have used compromising or other strategies to justify the decision to enroll in hospice, but there was no information in the transcripts to support that claim.

Pattison (1977) mapped a dying trajectory using a linear model. The short period of data collection, the wide range of lengths of stay and the limited sample size make comparing trajectories difficult; however most of the trajectories of the patients in the current study seem to be characterized by periods of slow deterioration and plateaus rather than by the linear trajectory or the disintegrated dying trajectory theorized by Pattison. Being able to identify a trajectory helps clinicians to be able to determine when a patient's needs may change, but it is possible that the conceptualizing of the death and dying as a linear process may not be consistent with the disease course of chronic illnesses.

Study Limitations

Recruitment of the sample in this study was very challenging. The study was not a study about hospice but instead about the experience of living with a life-limiting illness.

Two groups of people with a life-limiting illness comprised the pool of potential participants. Recruitment with the hospice population initially was going well, but during the first three months of the study the participants who participated in the study had been in the hospice program for at least a year and one participant had been in the program for 5 years. This wide variation in length of stay made comparisons difficult and entering into their lives for three weeks felt analogous to pouring a thimble of water into the Atlantic Ocean. At most the research would capture a snap shot, rather than a more comprehensive picture. There would not be an opportunity to follow the participants over a longer period of time to see how the picture evolved.

Additionally, no referrals were received from the home care group. The researcher was told that the home care program did not have people who met the study criteria. The researcher discussed possible data collection sites with the chair of the dissertation committee and then met with a faculty member from the College of Nursing who had a clinical practice in the community that served the African American community. The researcher was told that this practice also did not have people who would meet the inclusion criteria. The researcher wondered, if African Americans have a higher death rate for the top causes of death, heart disease, cancer, and chronic obstructive pulmonary disease, where are they receiving care at the end of life (Centers for Disease Control, 2000)?

Implications of the Study

Implications for Access to End of Life Care

Increasing access to palliative care services for African Americans has been identified as a goal of local and national initiatives (Crawley et al, 2000; Jackson et al., 2000). Outreach initiatives must focus on the three themes voiced in this study: the use

of life-affirming language and symbols, the integration of the philosophy of palliative care into belief systems of people who may be seeking hospice care and the role of the physician in the presentation of the hospice concept.

Physicians are the primary referral source and gatekeeper for hospice and palliative care services. Physicians may not have knowledge about the content of a palliative plan of care and therefore it may be difficult for physicians to help families to make a smooth transition from interventions that are focused on curing a disease to a comprehensive approach to palliative care. When people with a life-limiting illness and their families seek hospice or palliative care services, staff should be prepared to help the patient and family to see how the hospice philosophy can be incorporated into their beliefs and goals for palliative care. This message will need to be given multiple times over the course of the illness.

The hospice community has done a very good job of marketing hospice as the philosophy of care for people who are dying and their families. However, messages that promote the life-affirming nature of the hospice philosophy have been absent in many African American communities. Life-affirming messages should be incorporated in to any medium used to advertise or promote hospice and palliative care services, as well as into the language used by the staff when describing hospice and palliative care services.

Implications for Clinical Practice

People who are facing their deaths often communicate in symbolic language. For rural African Americans in north central Florida living with a life-limiting illness, this language is derived from religion and spirituality. Expressing a belief in healing does not

automatically mean that a person is unrealistic about the course of his or her illness. Healing can be used as a metaphor for renewal and resurrection in a spiritual sense as well as to symbolize healing of the physical body.

Clinicians should focus on the spoken and the symbolic language that are being used by the participants. A discussion of healing could be an opportunity for patients to express emotions in a language that provides comfort. This is also a good opportunity for the clinical staff to use the services of a spiritual care provider as an interpreter of the language and symbols so that all clinicians are able to provide support and guidance to the patient and family.

Comfort encompasses more than symptom management, and the power of palliative care lies in the work of an interdisciplinary team. "Keeping Faith" in the context of a life-limiting illness may require a new self-definition and reinterpretation of the criteria by which life is defined as meaningful. Addressing the issues of the fear of dependence, loss of control and fear of being a burden requires an interdisciplinary focus; first, to be able to hear what is being communicated about these issues and then to work with the participant to create new meaning if that is desired.

Implications for Research

Conducting clinical research with people who are living with a life-limiting illness is very challenging and resource intensive. Researchers are coming into the lives of the participants at a time when they are coping with emotional, physical and cognitive changes related to their diseases and striving to create a meaningful life. Interview guides should include questions that ask the participant about the many aspects of their lives and should not focus exclusively on death and dying topics.

Researchers who are proposing research studies in end of life care should incorporate staff input into the planning of a study, provide a format for a consistent explanation of the study and provide updates to the staff about the progress of the study. Collaboration with clinical staff in this study, included but was not limited to, talking with the staff before contacting the participant, respecting requests to delay interviews and making a joint visit with staff to meet participants.

Recommendations for Further Research

The purpose of this study was to develop a conceptual framework that would synthesize the experiences of African Americans living at home with a life-limiting illness. The basic social psychological problem was identified as “Affirming Life” and the basic social psychological process used to solve the problem was “Keeping Faith”

First, there is a need to expand on the work in the current study by comparing and contrasting the experiences of Black and White rural elders who are living with a life-limiting illness to provide more dimensions of the concepts in the process of “Keeping Faith,” such as the as the conditions that precipitate the process; identification of additional strategies used to manage the paradox between the God’s omnipotence and choosing or declining care; and the evolution of the process during the period of the illness.

Second, “Keeping Faith” in the context of a life-limiting illness may require a new self-definition and reinterpretation of the criteria by which life is defined as meaningful. Research is needed to describe how people with a life-limiting illness create a new self-definition and a new relationship with their changing body. Additionally, non-pharmacological symptom management strategies used by African Americans living with a life-limiting illness should be described.

Third, during the preparation of the proposal and data collection many words and phrases were used to describe people living with a life-limiting illness. Researchers should perform a concept analysis of the words life-limiting illness, terminal illness, serious illness and end stage of an illness. How are they used? What is the difference between the concepts? What are clinical indicators and empirical referents?

The participants used narratives to describe experiences while living with their illnesses. An opportunity for further research would be the examination of narratives used by people living with a life-limiting illness to identify the types of narratives used, the function of the narratives, the themes illustrated and the type of metaphors used in the narratives.

APPENDIX A
PERMISSION TO UTILIZE INTERVIEW PROTOCOL

re: letter

Subject: re: letter

Date: Tue, 25 Jun 2002 14:28:26 -0700

From: <Bill.Holzemer@nursing.ucsf.edu>

To: <cathcamp@ufl.edu>

CC: <hswilson@pacbell.net>

Cathy L. Campbell
Doctoral Candidate
University of Florida

Cathy,

This email serves as permission to utilize the interview protocol from the 1997 publication, "Salvaging Quality of Life in Ethnically Diverse Patients with ADvanced HIV/AIDS." I am sending this email to Dr. Wilson in case you wish to contact her directly.

Bill

William L. Holzemer, RN, PhD, FAAN
Associate Dean for International Programs
Director, WHO Collaborating Center
Professor, Department of Community Health Systems
School of Nursing, N531C
University of California, San Francisco
2 Koret Avenue
San Francisco, California 94143-0608 USA

Phone: 415-476-2763
Fax : 415-476-6042
Email: bill.holzemer@nursing.ucsf.edu

PLEASE REMIT ONE (1) SIGNED COPY OF THE AGREEMENT.
ALONG WITH ANY APPLICABLE PAYMENT TO THE ADDRESS LISTED ABOVE. THANK YOU.

APPENDIX B
UF CONSENT FORMS



UNIVERSITY OF FLORIDA

Health Center Institutional Review Board

PO Box 100173
Gainesville, Florida 32610-0173
Tele: (352) 846-1494
Fax: (352) 846-1497

MEMORANDUM

DATE: November 18, 2002

TO: Cathy L. Campbell, MSN, ARNP
Box 100187

FROM: R. Peter Iafrate, Pharm.D.
Chair, IRB-01

SUBJ: IRB Protocol #483-2002

Expires on 11/6/2003

TITLE: EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE LIVING WITH A LIFE-LIMITING
ILLNESS

On 11/6/02, this project was determined to be approvable pending changes. The required changes were approved on 11/15/2002 by an IRB Member. Your approval period is from 11/15/2002 - 11/5/2003. Enclosed is the dated, IRB-approved Informed Consent Form that must be used for enrolling subjects into this project during this time period.

You are responsible for applying for renewal of this project prior to the expiration date. Re-approval of this project must be granted before the expiration date or the project will be automatically suspended. If suspended, new subject accrual must stop. Research interventions must also stop unless there is a concern for the safety or well being of the subjects. You must respond to the continuing review questions within 90 days or your project will be officially terminated.

The IRB has approved exactly what was submitted. Any change in the research, no matter how minor, may not be initiated without IRB review and approval, except where necessary to eliminate hazards to human subjects. If a change is required due to a potential hazard, that change must be promptly reported to the IRB.

Any severe and unanticipated side effects or problems, and all deviations from federal, state, university or IRB regulations must be reported, in writing, within 5 working days.

Upon completion of the study, you are required to submit a CLOSURE REPORT to the IRB office.

Research records must be retained for three years after completion of the research; if the study involves medical treatment, it is recommended that the records be retained for eight years.

If VAMC patients will be included in this project, or if the project is to be conducted in part on VA premises or performed by a VA employee during VA-compensated time, review by the VA Subcommittee for Research is required.

You are responsible for notifying all parties about the approval of this project, including your co-Investigators and Department Chair. If you have any questions, please feel free to contact the IRB-01 office at (352) 846-1494.

Cc: IRB File
Pharmacy
VA Research Center
Clinical Research Center

IRB# 483-2002

Informed Consent to Participate in Research

<p>University of Florida Health Center Institutional Review Board APPROVED FOR USE From <u>11/15/02</u> Through <u>11/5/03</u> CJD</p>

You are being asked to take part in a research study. This form gives you information about the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the form below and ask questions about anything you do not understand. Being in the study is entirely your choice.

1. Name of Participant ("Study Subject")

2. Title of Research Study

Experiences and processes used by Black people living with a life-limiting illness

3. Principal Investigator and Telephone Number(s)

Cathy Campbell, RN, MSN, ARNP
(352) 271-9871

4. Source of Funding or Other Material Support

University of Florida

5. What is the purpose of this research study?

The purpose is to describe the lives of Black people who are facing a serious illness.

You are being asked if you would like to take part in this study because you are a Black person who has an illness with a limited life expectancy. There is little known about Black people who are living with a serious illness.



This study is being done to give Black people a chance to talk about what it is like to live with a serious illness. The total number of people who will take part in this study will be 20 people. Questions will be asked about the things that happen to you everyday, what you are learning, the quality of your life and death and dying. There are no right or wrong answers to any question.

6. What will happen if I agree to be in this study?

If you decide to be in this study your chart will be reviewed for documentation to confirm your primary diagnosis, disease-specific indicators or your doctor's certification of your life-limiting illness. Additionally you will be asked to be in audiotaped interviews at your home lasting 30-45 minutes each. You may be asked to take part in as many as three interviews. You can choose not to answer a question, stop the interview or stop the recording of any part or the whole interview at any time.

7. What are the possible discomforts and risks?

Talking about death and dying issues may cause discomfort, emotional upset or bring up other issues. The researcher will call the hospice office to report any change in your well-being. For interviews that are done Monday through Friday from 8 a.m. to 5 p.m. a team manager will be called and the on-call nurses will be called after 5:00 p.m. Monday through Friday, weekends and holidays. They will contact the person on the team that can best meet your needs at the time of your call.

If you wish to talk about the information above or any discomforts you may have, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

8a. What are the possible benefits to you?

You may benefit from talking about what it is like to live with a serious illness.

8b. What are the possible benefits to others?

What is learned from this study may help to make the care of people with a life-limiting illness better in the future.

9. If you choose to take part in this research study, will it cost you anything?

There will be no charge for you to be in this study.

10. Will you receive compensation for taking part in this research study?

There will be no payment for taking part in this research study.



11. What if you are injured because of the study?

If you have an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be given to you without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other payment will be offered to you.

12. What other options or treatments are available if you do not want to be in this study?

If you do not want to be in this study, the other choice is doing nothing. If you do not want to take part in this study, tell the Principal Investigator or her assistant and do not sign this Informed Consent Form.

13a. Can you withdraw from this research study?

You are free to leave this research study at any time. If you do not choose to be in the study, there will be no penalty, you will not lose any benefits you are entitled to and the care you are receiving will not change.

If you choose to not to be in this research study for any reason, you should contact Cathy Campbell at (352) 271-9871.

If you have any questions about your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

13b. If you withdraw, can information about you still be used and/or collected?

If you choose not to be in this study the information collected while you were in the study may be used, but you will have no more visits from the researcher.

13c. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

1. You do not meet the study requirements. Ask the Principal Investigator if you would like to know more about this.
2. The investigator decides that being in the study would be harmful to you.
3. You cannot keep appointments or take part in the scheduled interviews.



14. How will your privacy and the confidentiality of your research records be protected?

Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will be kept confidential.

The information received during the interviews and chart review will be kept confidential. A number and the date of interview will be written on the audiotapes. During your interview the researcher may take notes. The notes will also have the same number and date as the audiotapes. No information about you will appear on the tape or cassette case. Only the researcher will have a list that links the number written on the audiotape with your name and address.

A person will type what is recorded on the tape. There will be no information about you given to the typist. The tapes, notes, list of names and addresses and the pages that were typed by the typist will be kept at the university office of the researcher in a locked cabinet.

15. How will the researcher(s) benefit from your being in this study?

In general, sharing research results helps the career of a researcher. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

**16. Signatures**

As a representative of this study, I have explained to the participant the purpose, what will happen if he/she agrees to be in the study, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Signature of Person Obtaining Consent

Date

You have been informed about this study's purpose, what will happen if you agree to be in the study, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You have received a copy of this Form. You have been given the chance to ask questions before you sign, and you have been told that you can ask other questions at any time.

You freely agree to be in this study. By signing this form, you are not giving up any of your legal rights.

Signature of Person Consenting

Date

APPENDIX C
HOSPICE APPROVAL LETTER

HOSPICE
OF NORTH CENTRAL FLORIDA

6 December 2002

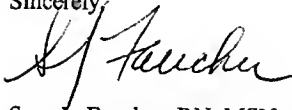
Dear Cathy,

Thank you so much for your patience with our Research Committee and for coming back a second time to re-present your proposal. We are very pleased to tell you that our committee and IRB have given approval and will support you to begin in January, 2003.

As discussed, you may plan to present a summary of your research proposal at our upcoming Senior Clinician meeting on January 8, 2003. Plan to take about 15 minutes for the overview and then a question/answer session. You may also begin to identify potential participants through the Intake and Referral Department anytime with plans to begin actual data collection after your initial presentation to the Senior Clinician staff.

We look forward to working with you on this project. If you have any questions, need help or have concerns, please feel free to contact me.

Sincerely,



Sara-Jo Faucher, RN, MSN, Geri-CNS, CHPN
Director of Clinical Services

APPENDIX D
PATIENT RECRUITMENT LETTER




UNIVERSITY OF
FLORIDA

Health Center Institutional Review Board

PO Box 100173
Gainesville, Florida 32610-0173
Tel: (352) 846-1494
Fax: (352) 846-1497

MEMORANDUM

DATE: January 16, 2003
TO: Cathy L. Campbell, MSN, ARNP
Box 100187
FROM: Keith R. Peters, M.D.
Vice Chairman, IRB - 01 
SUBJECT: Revision of IRB Project #483-2002
TITLE: EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE LIVING WITH A LIFE-LIMITING ILLNESS

On 1/16/2003 the IRB reviewed and APPROVED the submitted revision(s) listed below:

Addition of a study announcement letter to facilitate recruitment.

A copy of the revision letter dated 1/14/2003 has been stamped with the date of IRB approval and is enclosed.

Thank you for keeping the IRB informed about your research project, thereby allowing us to keep accurate files. If the IRB staff can be of any further assistance, please feel free to call.

encl: Dated, IRB-approved Revision Letter

cc: IRB file
Pharmacy

University of Florida Health Science Center • Institutional Review Board (IRB-01)

PROJECT REVISION

Please provide contact information for a representative who can answer any questions that the IRB might have concerning this submission:

Name:	Cathy Campbell, MSN, ARNP
Position:	Principal Investigator
E-mail:	cathcamp@ufl.edu
Phone #:	352-271-9871
Pager #:	
2 nd Contact:	name + e-mail or phone #
Group:	*select if applicable*

This box is for IRB-01 use ONLY.

Rcd 1/9/03

IRB
APPROVED
ON 1/14/03
ca

Expiration date:

Form Instructions:

- All changes, no matter how minor, must be submitted for review and approval by the IRB before they are implemented. See the last page of this form for additional instructions.
- Submit five copies (the signed original plus four photocopies) of your submission to the IRB-01 office. You must provide copies of all paperwork including grants, articles, etc. You should also retain one copy of the submission for your files.
- All submissions must be typed.
- This form is available on the IRB-01 website at: <http://irb.ufl.edu/irb01/forms.htm>

1. Date: 1/9/2003
2. Principal Investigator: Cathy Campbell, MSN, ARNP
3. IRB Project #: 483-2002
4. Project Title: Experiences and processes used by Black people living with life-limiting illness
5. What is the revision? Addition of a study announcement letter
6. What is the justification for and/or the purpose of the revision? The letter will be used by the clinical staff at Hospice of North Central Florida and Florida Palliative Home Care to introduce the study to potential subjects. Introduction of the letter will facilitate subject recruitment and provide a consistent format to introduce the study
7. This is a: ☒ MINOR revision involving minimal risk to research subjects
(select one) ☐ MAJOR revision involving greater than minimal risk to research subjects.
8. Indicate what materials are being submitted along with this form:

- | | |
|---|--|
| <input checked="" type="checkbox"/> Advertisement. | <input type="checkbox"/> Principal Investigator change (Major revision). |
| <input type="checkbox"/> Drug package insert. | <input type="checkbox"/> Protocol amendment. |
| <input type="checkbox"/> Informed Consent Form. | <input type="checkbox"/> Sub-investigator change. |
| <input type="checkbox"/> Investigator's Brochure. | <input type="checkbox"/> Title change. |
| <input type="checkbox"/> Introductory Questionnaire | <input type="checkbox"/> Other: (Please list) <input type="text"/> |

9. Has this revision already been implemented?

☒ No

☐ Yes. Explain when and why it was implemented:

10. List any specific information that needs to be included in the IRB response letter.

Not applicable

Cathy L Campbell
Signature of Principal Investigator
Cathy Campbell, MSN, ARNP

1/9/03
Date

DATE: January 14, 2003
TO: Keith R. Peters, M.D.
Vice Chairman, IRB-01
RE: Executive Review of Revision

IRB
APPROVED
ON 1/14/03
cl

PROJ: 483-2002 EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE
LIVING WITH A LIFE-LIMITING ILLNESS

Dr. Peters:

Attached you will find the revised copy of the study announcement letter for Project 483-2002. As requested the addition to the document is underlined.

Sincerely yours,

Cathy L. Campbell
Cathy L. Campbell, MSN, ARNP
Primary Investigator

INSTITUTIONAL
JAN 14 2003
CLM 00120

cc: Dr. Carol Reed Ash
Supervisory Chairperson

You are being asked to be in a research study done by Cathy Campbell, a nurse and doctoral student from the College of Nursing at the University of Florida. The purpose of this study is to describe the lives of Black people who are facing a serious illness, therefore, it is important to talk with Black men and women who are living with a serious illness. What is learned from this study may help to improve the care of people with a life-limiting illness in the future.

Being in the study is entirely your choice. The care you are getting will not be changed or affected by your being in the study or your choice not to be in the study.

Ms. Campbell will describe this study to you and give you time to ask questions about the study and to have your questions answered. If you agree to be in the study she will ask you to sign a consent form that indicates that you have chosen to be in the study and understand the information in the consent form.

- If you choose to be in this study your chart will be reviewed only once for documentation to confirm your primary diagnosis, disease-specific indicators or your doctor's certification of your life-limiting illness.
- You may be asked to take part in as many as three audiotaped interviews that will last 30-45 minutes. You can choose not to answer a question, stop the interview or stop the recording of any part or the whole interview at any time.
- During the interviews questions will be asked about the things that happen to you everyday, what you are learning, the quality of your life and death and dying. There are no right or wrong answers to any question.

If you want to be in the study, give a member of your clinical team permission to give your name and phone number to Ms. Campbell, the researcher. She will call you and set a time to talk with you about the study.

Thank you very much.

Cathy Campbell, MSN, ARNP

IRB
APPROVED
ON 1/16/03
ae

APPENDIX E
HIPPA AUTHORIZATION



UNIVERSITY OF
FLORIDA

Health Science Center Institutional Review Board

PO Box 100173
Gainesville, Florida 32610-0173
Tel: (352) 846-1494
Fax: (352) 846-1497

MEMORANDUM

DATE: April 21, 2003
TO: Cathy L. Campbell, MSN, ARNP
Box 100187
FROM: Michael Scian, MBA, JD *Michael Scian*
HIPAA Coordinator
RE: **HIPAA Authorization**
PROJECT: 483-2002 EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE LIVING WITH A
LIFE-LIMITING ILLNESS

On 4/21/2003 the IRB reviewed your HIPAA Authorization form for compliance with HIPAA regulations. This submission has been APPROVED. A copy of the HIPAA Authorization has been stamped with the date of IRB approval and is enclosed.

NOTE: Please remember that all subjects enrolled into this project after April 13th, 2003 must sign the enclosed Authorization form AND an IRB approved Informed Consent form.

Thank you for keeping the IRB informed about your research project, thereby allowing us to keep accurate files. Please contact us if we can be of any further assistance.

University of Florida Health Science Center • Institutional Review Board (IRB-01)

HIPAA AUTHORIZATION FOR PROJECTS APPROVED BEFORE 04/13/2003 AND ENROLLING NEW SUBJECTS AFTER 4/13/2003

Please provide contact information for a representative who can answer any questions that the IRB might have concerning this submission:

Name:	Cathy Campbell, MSN, ARNP
Position:	Principal Investigator
E-mail:	cathcamp@ufl.edu
Phone #:	352-271-9871
Pager #:	
2 nd Contact:	name + e-mail or phone number
Group:	*select if applicable*

This box is for IRB-01 use ONLY.

**IRB
APPROVED
ON 4/21/03 m-s**

Form Instructions:

- Enter the information in the appropriate fields on this page. This information will then pre-populate into the appropriate areas throughout the rest of the authorization.
- You will need to provide specific information after the following questions on the authorization: 3, 4, 5, 6, and 7. Each of these questions has a line with the text <Type your response here>. Delete this text and enter your answer. Instructions on how to answer the question are in a box following this line. Delete the instruction box after answering the question.
- For question 5.e. enter the study sponsor as indicated in the parentheses. If your study does not have a sponsor, delete the entire line.
- All submissions must be typed.
- Submit two copies (the signed original plus one photocopy) of this entire form.
- This form is available on the IRB-01 website at: <http://irb.ufl.edu/irb01/hipaafoms.htm>

Date: April 9, 2003

IRB Project #: 483-2002

Project Title: Experiences and processes used by Black people living with a life-limiting illness

Principal Investigator: Cathy L. Campbell, MSN, ARNP

Cathy L. Campbell
Signature of Principal Investigator
Cathy L. Campbell, MSN, ARNP

4/9/03
Date

HIPAA Authorization for IRB # 483-2002



**RESEARCH SUBJECT
AUTHORIZATION TO COLLECT, USE AND DISCLOSE PROTECTED HEALTH
INFORMATION FOR RESEARCH PURPOSES**

IRB Project#: 483-2002

Project Title: Experiences and processes used by Black people living
with a life-limiting illness

Principal Investigator: Cathy L. Campbell, MSN, ARNP

Purpose: The purpose of this form is to ask you to authorize the collection, use, and disclosure of your protected health information in connection with this research study.

1. Why are you being asked to authorize the collection, use and disclosure to others of your protected health information?

Under a new Federal Law, researchers cannot collect, use or disclose any of your protected health information for research unless you allow them to by signing this authorization.

2. Are you required to sign this authorization and allow the researchers to collect, use and disclose (give) to others of your protected health information?

No, and your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. *However, you cannot participate in this research unless you allow the collection, use and disclosure of your protected health information by signing this consent/authorization.*

3. If you sign this authorization and agree to participate in this research study, what protected health information about you may be collected, used and disclosed to others?

To determine your eligibility for the study and as part of your participation in the study, your protected health information that is obtained from you, from review of your past or current health records, from procedures such as physical examinations, x-rays, blood or urine tests or other procedures, from your response to any study treatments you receive, from your study visits and phone calls, and any other study related health information may be collected, used and disclosed to others. More specifically, the following information may be collected, used, and disclosed to others:

Name	Address	Age
Phone number		
Date of certification of life-limiting illness		



The researcher will review the clinical record for the primary diagnosis and documentation of a physician's certification of a life expectancy of six months or less or documentation of core and disease-specific indicators that would be documented in medical histories, physical exams, laboratory, x-ray, and other test results.

4. For what study-related purposes will your protected health information be collected, used and disclosed to others?

Your protected health information may be collected, used and disclosed to others to find out your eligibility for, to carry out, and to evaluate the results of the research study. More specifically, your protected health information may be collected, used and disclosed for the following study-related purpose(s):

The purpose is to describe the lives of Black people who are facing a serious illness.

You are being asked if you would like to take part in this study because you are a Black person who has an illness with a limited life expectancy. There is little known about Black people who are living with a serious illness.

5. Who will be authorized to collect use and disclose to others your protected health information?

Your protected health information may be collected, used, and disclosed to others by

- a. the study principal investigator (Cathy L. Campbell, MSN, ARNP) and his/her staff
- b. the University of Florida Institutional Review Board
- c. Dissertation supervisory committee at University of Florida
- d. Hospice of North Central Florida Research Committee
- e. Clinical staff of Hospice of North Central Florida or Florida Palliative Homecare

6. Once collected or used, who may your protected health information be disclosed to?

Your protected health information may be given to:

- US and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections
- Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and Federal, State and local health departments

7. If you agree to participate in this research, how long will your protected health information be used and disclosed?

Until the end of the study.



8. Can you review or copy your protected health information collected, used or disclosed under this authorization?

You have the right to review and copy your protected health information. However, you will not be allowed to do so until after the study is finished.

9. Is there a risk that your protected health information could be given to others beyond your authorization?

Yes. There is a risk that information received by authorized persons could be given to others beyond your authorization and not covered by the law.

10. Can you revoke (cancel) your authorization for collection, use and disclosure of your protected health information?

Yes. You can revoke your authorization at any time before, during or after your participation in the research. If you revoke, no new information will be collected about you. However, information that was already collected may be still be used and disclosed to others if the researchers must rely on it to complete and protect the validity of the research. You can revoke by giving a written request with your signature on it to the Principal Investigator.



By signing this form, the research subject or research subject's legal representative authorizes the collection, use, and disclosure of the research subject's protected health information as described in this form.

Printed Name of Person obtaining authorization
(Principal Investigator or delegate): _____

Signature of Person obtaining authorization
(Principal Investigator or delegate): _____
Signature Date

Printed Name of Research Subject granting
authorization (must be completed **unless**
subject is a minor or otherwise incompetent to
execute this authorization): _____

Signature of Research Subject granting
authorization (must be completed **unless**
subject is a minor or otherwise incompetent to
execute this authorization): _____
Signature Date

Printed Name of legal representative or legal
guardian (must be completed **only** if subject is
a minor or otherwise incompetent to execute
this authorization): _____

Signature of legal representative or legal
guardian (must be completed **only** if subject is
a minor or otherwise incompetent to execute
this authorization): _____
Signature Date

Description of legal representative or legal
guardian's legal authority to sign for the
research subject. (must be completed **only** if
subject is a minor or otherwise incompetent to
execute this authorization). For example:
"father/mother of minor child"; or "court
appointed legal guardian"; or "designated
health care surrogate"; or "attorney-in-fact
pursuant to durable power of attorney": _____

APPENDIX F
VETERANS ADMINISTRATION DOCUMENTATION

**Department of
Veterans Affairs**

Memorandum

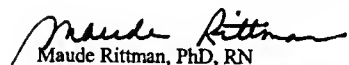
Date: July 2, 2003
From: Maude Rittman, Ph.D., RN
Subj: Protocol #483-2002: Experience and processes used by Black people living with a life-limiting illness
To: Peter Iafrate, Pharm. D., Chair, IRB-01

1. I am pleased to be a co-investigator for this study. As a co-investigator, I have the responsibility for assisting Cathy Campbell, the doctoral student who is the Principal Investigator, in conducting the study and to do so ethically, for protecting the rights and welfare of the human subjects, and for strictly adhering to any stipulations imposed by the Institutional Review Board. In the VA I agree to serve as the Co-Principal Investigator to facilitate the study being conducted at the VA.

2. I agree to assist Ms. Campbell in complying with all UF policy and procedures as well as all applicable federal, state and local laws regarding the protection of human subjects in research, including, but not limited to the following:

- Ensuring that only qualified personnel conduct the study according to the approved protocol and in compliance with each individual's scope of practice.
- Implementing no changes in the approved Protocol or Informed Consent Form without prior institutional Review Board Approval, except in an emergency, if necessary to safeguard well-being of human subjects.
- Obtaining legally effective informed consent from human subjects or their legally responsible representative before any research-related screening commences and using only the currently approved, stamped informed consent form.
- Promptly reporting serious and unexpected adverse events to the Institutional Review Board (IRB) in writing within 5 working days of occurrence or notification of occurrence.
- Completing investigator training as required by the IRB.

3. Thank you in advance for considering this request.


Maude Rittman, PhD, RN
Rehabilitation Outcomes Research Center
North Florida/South Georgia Veterans Health System

CC: Dr. Carol Reed Ash, College of Nursing, Supervisory Chairperson
Cathy Campbell, Doctoral Candidate, Principal Investigator



REPORT OF SUBCOMMITTEE ON HUMAN STUDIES

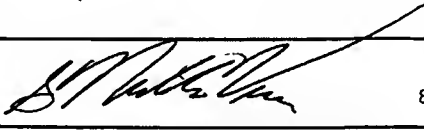
Project/Program Title	Experiences and Processes Used by Black People Living with a Life-Limiting Illness		
Principal Investigator	Maude Rittman, PhD		
VAMC Gainesville, FL	Review Date	11/15/02	IRB #483-02

COMMITTEE FINDINGS

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or surrogate who possesses standard reading and comprehension skills. ☒ YES
☐ NO
2. The informed consent is obtained by the principal investigator or a trained and supervised designate under suitable circumstances. ☒ YES
☐ NO
3. Every effort has been made to decrease risk to subject(s)? ☒ YES
☐ NO
4. The potential research benefits justify the risk to subject(s)? ☒ YES
☐ NO
5. If the subject is incompetent and surrogate consent is obtained, have all of the following conditions been met: a) the research can't be done on competent subjects; b) there is no risk to the subject, or if risk exists the direct benefit to subject is substantially greater; c) If an incompetent subject resists, he/she will not have to participate; d) If there exists any question about the subject's competency, the basis for decision on competency has been fully described. ☒ YES
☐ NO
☐ NA
6. If the subject is paid, the payment is reasonable and commensurate with the subject's contribution. ☐ YES
☐ NO
☒ NA
7. Members of minority groups and women have been included in the study population whenever possible and scientifically desirable. ☒ YES
☐ NO
8. Comments: (Indicate if Expedited Review)

Approved by the Research and Development Committee on 8/11/03.

RECOMMENDATION: ☒ APPROVED ☐ DISAPPROVE/REVISE

SIGNATURE OF CHAIRMAN	DATE
G. NICHOLAS VERNE, M.D. 	8/11/03

VA FORM 10-1223
OCT 1995

EXISTING STOCK OF VAF 10-1223,
JAN 1990, WILL NOT BE USED



Health Center Institutional Review Board

PO Box 100173
Gainesville, Florida 32610-0173
Tel: (352) 846-1494
Fax: (352) 846-1497

MEMORANDUM

DATE: August 7, 2003
TO: Cathy L. Campbell, MSN, ARNP
Box 100187
FROM: R. Peter Iafrate, Pharm.D.
Chairman, IRB - 01
SUBJECT: Revision of IRB Project #483-2002
TITLE: EXPERIENCES AND PROCESSES USED BY BLACK PEOPLE LIVING WITH A LIFE-LIMITING ILLNESS

A handwritten signature in black ink, reading "R. Peter Iafrate".

On 8/7/2003 the IRB reviewed and APPROVED the submitted revision(s) listed below:

To the VA Informed Consent Form: Added Maude Rittman, PhD as investigator, simplified language in section 6, and added UF boilerplate to section 11.

To UF Informed Consent Form: simplified language in section 6.

A copy of the revision letter dated 8/4/2003 has been stamped with the date of IRB approval and is enclosed.

Thank you for keeping the IRB informed about your research project, thereby allowing us to keep accurate files. If the IRB staff can be of any further assistance, please feel free to call.

encl: Dated, IRB-approved Revision Letter

cc: IRB file
Pharmacy

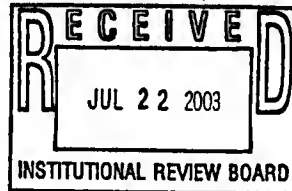
University of Florida Health Science Center • Institutional Review Board (IRB-01)

PROJECT REVISION

Please provide contact information for a representative who can answer any questions that the IRB might have concerning this submission:

Name:	Cathy L. Campbell, MSN, ARNP
Position:	Principal Investigator
E-mail:	cathcamp@ufl.edu
Phone #:	352-271-9871
Pager #:	
2 nd Contact:	name + e-mail or phone #
Group:	*select if applicable*

This box is for IRB-01 use ONLY.



Expiration date:

Form Instructions:

- All changes, no matter how minor, must be submitted for review and approval by the IRB before they are implemented. See the last page of this form for additional instructions.
- Submit five copies (the signed original plus four photocopies) of your submission to the IRB-01 office. You must provide copies of all paperwork including grants, articles, etc. You should also retain one copy of the submission for your files.
- Submissions that do not meet our Submission Acceptability Standards will be returned to the PI. Visit <http://irb.ufl.edu/irb01/formsubmit.htm> for more information.
- All submissions must be typed.
- This form is available on the IRB-01 website at: <http://irb.ufl.edu/irb01/forms.htm>

1. Date: 7/21/2003
2. Principal Investigator: Cathy L. Campbell, MSN,
ARNP
3. IRB Project #: 483-2002
4. Project Title: Experiences and processes used by Black people living with a life-
limiting illness

**IRB
APPROVED**
ON 08/07/03

5. What is the revision? All revisions are to the VA informed consent document

1. Adding Dr. Rittman's name to the informed consent document in section 3 and in the header of informed consent document

2. Adding the UF required statement regarding compensation if injured to section 11

3. Adding simplified terms to section 6 for "primary diagnosis" and disease-specific indicators

6. What is the justification for and/or the purpose of the revision? Revisions requested by the VA Subcommittee for Clinical Investigation

7. This is a: ☒ MINOR revision involving minimal risk to research subjects
(select one) ☐ MAJOR revision involving greater than minimal risk to research subjects.

8. Indicate what materials are being submitted along with this form:

- | | |
|--|---|
| <input type="checkbox"/> Advertisement. | <input type="checkbox"/> Introductory Questionnaire |
| <input type="checkbox"/> Drug package insert. | <input type="checkbox"/> Principal Investigator change (Major revision) |
| <input checked="" type="checkbox"/> Informed Consent Form. | <input type="checkbox"/> Protocol amendment. |
| <input type="checkbox"/> Informed Consent Form (add HIPAA) | <input type="checkbox"/> Sub-investigator change. |
| <input type="checkbox"/> Investigator's Brochure. | <input type="checkbox"/> Title change. |
| <input checked="" type="checkbox"/> Other. (Please list) <u>Memorandum from VA Subcommittee for Clinical Investigation</u> | |

9. Has this revision already been implemented?

☒ No

☐ Yes. Explain when and why it was implemented:

10. List any specific information that needs to be included in the IRB response letter.

Cathy L Campbell
Signature of Principal Investigator
Cathy L. Campbell, MSN, ARNP

7/21/03
Date

Department of Veterans Affairs

Memorandum

Date: July 11, 2003

From: Chairperson, Subcommittee for Clinical Investigation (SCI)

Subj: "Experiences and Processes Used by Black People Living with a Life-Limiting Illness" IRB #483-02

To: Maude Rittman, RN, Ph.D.

**IRB
APPROVED**
ON 08/07/03

The Subcommittee for Clinical Investigation (SCI) reviewed the above protocol at its July 11, 2003 meeting. The Subcommittee has approved this protocol pending receipt of a revised informed consent.

Following is a list of recommendations for approval of this protocol; if you do not agree with our recommendations, please provide a written justification to Faye in Research Services.

Informed Consent:

Please add Dr. Rittman's name to the informed consent in section 3 and in the header.

Add the UF required statement regarding compensation if injured to section 11.

Please add simplified terms to section 6 for "primary diagnosis" and "disease-specific indicators."

Training Requirement: Human Participant Protections Education for Research Teams and Good Clinical Practice (GCP) training documents are required for all investigators, co-investigators, and sub-investigators annually. You can access the National Cancer Institute's (NCI) web-based course on Human Participant Protections Education for Research Teams at <http://cme.nci.nih.gov>. The VA Employee Education System provides a web-based training course on the basics of Good Clinical Practices at http://www.va.gov/resdev/ft/stand_down. Certificates must be received by the Research Office prior to initiation of the study and must be updated annually thereafter.

VA-approved research is contingent upon approval by the Veterans Affairs Research and Development Committee (R&D) as well as the SCI. SCI and IRB approval are both required prior to review by the Research and Development Committee. Upon receiving IRB full approval, please provide a copy of the IRB approval letter and stamped informed consent to Faye Coopender so that your protocol can be reviewed at the next R&D Committee meeting. You may fax the approval and informed consent to Faye at (352) 374-6170. Research may begin following R&D Committee approval; a VA approval form (form 10-1223) will be sent to you as confirmation of VA Research and Development Committee approval. The R&D Committee meets monthly and scheduled meetings are: August 11th and September 8th.

If you have questions you may reach Faye at (352) 376-1611 x.5268.

G. NICHOLAS VERNE, M.D.

Cc: Research Office

Cathy Campbell, RN, MSN, ARNP

Reminder: Health Center IRB approval is required: (1) prior to initiating studies at the Gainesville VAMC; and (2) for all protocol/informed consent revisions. Please be sure that any modifications/additions/etc. submitted to the Health Center IRB are also submitted to the Gainesville VAMC for approval along with the appropriate cover form.

August 4, 2003

TO: Dr. Keith Peters
Vice Chairman, IRB 01

FROM: Cathy Campbell, MSN, ARNP

RE: 483-2002
Experiences and processes used by Black people living with a life-limiting illness

**IRB
APPROVED**
ON 08/07/03


Attached is a clean copy of the VA informed consent form with the footer corrected as requested in the August 1, 2003 executive review memorandum.


MEMORANDUM

DATE: August 4, 2003

TO: Keith Peters, MD
Vice Chairman, IRB-01

FROM: Cathy L. Campbell, MSN, ARNP
Box 100187

RE: Executive Review of Revision

**IRB
APPROVED**
ON 08/07/03 

PROJ: 483-2002 EXPERIENCES AND PROCESSES USED BY
BLACK PEOPLE LIVING WITH A LIFE-LIMITING ILLNESS

Enclosed you will find the following changes as requested:


Copies of the UF consent form with the same changes made, specifically those in Item 6 and Item 11.

Running footer corrected so that it shows the correct pagination.

The Item 6 changes were: Change the first sentence to: "If you decide to be in this study your chart will be reviewed for documentation to confirm your illness, symptoms or test results related to your illness or your doctor's certification of your life-limiting illness."

The Item 11 changes requested were: Please add as the second paragraph: "If you have an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be given to you without charge. However, hospital expenses will have to be paid to you or your insurance provider. No other payment will be offered to you."

The language requested in item 11 is already present on the original form that was submitted and approved by the IRB in November 2002. Therefore, that section will not be underlined (to reflect new content added) since it is not a new addition.

 Department of Veterans Affairs	VA RESEARCH CONSENT FORM
Subject Name: _____	Date: _____
Title of Study: <u>Experiences and processes used by black people living with a life-limiting illness</u>	
Principal Investigator: <u>Maude Rittman, PhD</u>	VAMC: <u>Gainesville</u>

IRB# 483-02

Informed Consent to Participate in Research

University of Florida
Health Center
Institutional Review Board
APPROVED FOR USE
From 08/07/03 Through 11/05/03

You are being asked to take part in a research study. This form gives you information about the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the form below and ask questions about anything you do not understand. Being in the study is entirely your choice.

1. **Name of Participant ("Study Subject")**

2. **Title of Research Study**

Experiences and processes used by Black people living with a life-limiting illness


3. **Principal Investigator and Telephone Number(s)**
Maude Rittman, PhD
North Florida/South Georgia Veterans Health System
(352) 374-6108

Cathy Campbell, RN, MSN, ARNP
(352) 271-9871

4. **Source of Funding or Other Material Support**

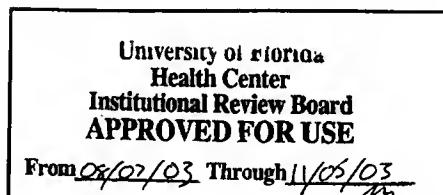
Department of Veterans Affairs		VA RESEARCH CONSENT FORM	
Subject Name: _____	Date: _____		
Title of Study: <u>Experiences and processes used by black people living with a life-limiting illness</u>			
Principal Investigator: <u>Maude Rittman, PhD</u>		VAMC: <u>Gainesville</u>	
<p>University of Florida</p> <p>5. What is the purpose of this research study?</p> <p>The purpose is to describe the lives of Black people who are facing a serious illness.</p> <p>You are being asked if you would like to take part in this study because you are a Black person who has an illness with a limited life expectancy. There is little known about Black people who are living with a serious illness.</p> <p>This study is being done to give Black people a chance to talk about what it is like to live with a serious illness. The total number of people who will take part in this study will be 20 people. Questions will be asked about the things that happen to you everyday, what you are learning, the quality of your life and death and dying. There are no right or wrong answers to any question.</p> <p>6. What will happen if I agree to be in this study?</p> <p>If you decide to be in this study your chart will be reviewed for documentation to confirm your illness, symptoms or test results related to your illness or your doctor's certification of your life-limiting illness. Additionally you will be asked to be in audiotaped interviews at your home lasting 30-45 minutes each. You may be asked to take part in as many as three interviews. You can choose not to answer a question, stop the interview or stop the recording of any part or the whole interview at any time.</p> <p>7. What are the possible discomforts and risks?</p> <p>Talking about death and dying issues may cause discomfort, emotional upset or bring up other issues. The researcher will call the Home based Primary Care office to report any change in your well-being. For Home Based Primary Care patients the procedure is as follows: For interviews that are done Monday through Friday from 8 a.m. to 4:00 p.m. the HBPC office will be contacted and after 4:00 p.m. the physician on-call in the Gainesville VA emergency room will be called to initiate follow-up as indicated.</p> <p>If you wish to talk about the information above or any discomforts you may have, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.</p> <p>8a. What are the possible benefits to you?</p> <p>You may benefit from talking about what it is like to live with a serious illness.</p>			

Department of Veterans Affairs		VA RESEARCH CONSENT FORM	
Subject Name: _____	Date: _____		
Title of Study: <u>Experiences and processes used by black people living with a life-limiting illness</u>			
Principal Investigator: <u>Maude Rittman, PhD</u>		VAMC: <u>Gainesville</u>	
<p>8b. What are the possible benefits to others?</p> <p>What is learned from this study may help to make the care of people with a life-limiting illness better in the future.</p> <p>9. If you choose to take part in this research study, will it cost you anything?</p> <p>There will be no charge for you to be in this study.</p> <p>Costs for routine medical care procedures that are not being done only for the study will be charged to you or your insurance. These costs may not be charged if you are a veteran and you are being treated at the North Florida/South Georgia Veterans Health System (NF/SG VHS).</p> <p>10. Will you receive compensation for taking part in this research study?</p> <p>There will be no payment for taking part in this research study.</p> <p>11. What if you are injured because of the study?</p> <p>You will not have to pay hospital expenses if you are being treated at the North Florida/South Georgia Veterans Health System (NF/SG VHS) and experience any physical injury during participation in a Veterans Health System-approved study.</p> <p>If you have an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be given to you without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other payment will be offered to you.</p> <p>12. What other options or treatments are available if you do not want to be in this study?</p> <p>If you do not want to be in this study, the other choice is doing nothing. If you do not want to take part in this study, tell the Principal Investigator or her assistant and do not sign this Informed Consent Form.</p> <p>13a. Can you withdraw from this research study?</p>			

 Department of Veterans Affairs	VA RESEARCH CONSENT FORM
Subject Name: _____ Date _____	
Title of Study: <u>Experiences and processes used by black people living with a life-limiting illness</u>	
Principal Investigator: <u>Maude Rittman, PhD</u> VAMC: <u>Gainesville</u>	
<p>You are free to leave this research study at any time. If you do not choose to be in the study, there will be no penalty, you will not lose any benefits you are entitled to and the care you are receiving will not change.</p> <p>If you choose to not to be in this research study for any reason, you should contact Cathy Campbell at (352) 271-9871.</p> <p>If you have any questions about your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.</p> <p>13b. If you withdraw, can information about you still be used and/or collected?</p> <p>If you choose not to be in this study the information collected while you were in the study may be used, but you will have no more visits from the researcher.</p> <p>13c. Can the Principal Investigator withdraw you from this research study?</p> <p>You may be withdrawn from the study without your consent for the following reasons:</p> <ol style="list-style-type: none"> 1. You do not meet the study requirements. Ask the Principal Investigator if you would like to know more about this. 2. The investigator decides that being in the study would be harmful to you. 3. You cannot keep appointments or take part in the scheduled interviews. <p>14. How will your privacy and the confidentiality of your research records be protected?</p> <p>Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.</p> <p>If the results of this research are published or presented at scientific meetings, your identity will be kept confidential.</p> <p>The information received during the interviews and chart review will be kept confidential. A number and the date of interview will be written on the audiotapes. During your interview the researcher may take</p>	

Department of Veterans Affairs		VA RESEARCH CONSENT FORM	
Subject Name:		Date	
Title of Study:	Experiences and processes used by black people living with a life-limiting illness		
Principal Investigator:	Maude Rittman, PhD	VAMC:	Gainesville
<p>notes. The notes will also have the same number and date as the audiotapes. No information about you will appear on the tape or cassette case. Only the researcher will have a list that links the number written on the audiotape with your name and address.</p> <p>A person will type what is recorded on the tape. There will be no information about you given to the typist. The tapes, notes, list of names and addresses and the pages that were typed by the typist will be kept at the university office of the researcher in a locked cabinet.</p> <p>15. How will the researcher(s) benefit from your being in this study?</p> <p>In general, sharing research results helps the career of a researcher. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.</p> <p>16. Signatures</p> <p>As a representative of this study, I have explained to the participant the purpose, what will happen if he/she agrees to be in the study, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:</p> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between;"> </div> <div style="display: flex; justify-content: space-between;"> Signature of Person Obtaining Consent Date </div> </div> <p style="margin-top: 10px;">You have been informed about this study's purpose, what will happen if you agree to be in the study, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You have received a copy of this Form. You have been given the chance to ask questions before you sign, and you have been told that you can ask other questions at any time.</p> <p style="margin-top: 10px;">You freely agree to be in this study. By signing this form, you are not giving up any of your legal rights.</p> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between;"> </div> <div style="display: flex; justify-content: space-between;"> Signature of Person Consenting Date </div> </div>			

IRB# 483-02

Informed Consent to Participate in Research

You are being asked to take part in a research study. This form gives you information about the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the form below and ask questions about anything you do not understand. Being in the study is entirely your choice.

1. Name of Participant ("Study Subject")

2. Title of Research Study

Experiences and processes used by Black people living with a life-limiting illness

3. Principal Investigator and Telephone Number(s)

Cathy Campbell, RN, MSN, ARNP
(352) 271-9871

4. Source of Funding or Other Material Support

University of Florida

5. What is the purpose of this research study?

The purpose is to describe the lives of Black people who are facing a serious illness.

You are being asked if you would like to take part in this study because you are a Black person who has an illness with a limited life expectancy. There is little known about Black people who are living with a serious illness.



This study is being done to give Black people a chance to talk about what it is like to live with a serious illness. The total number of people who will take part in this study will be 20 people. Questions will be asked about the things that happen to you everyday, what you are learning, the quality of your life and death and dying. There are no right or wrong answers to any question.

6. What will happen if I agree to be in this study?

If you decide to be in this study your chart will be reviewed for documentation to confirm your illness, symptoms or test results related to your illness or your doctor's certification of your life-limiting illness. Additionally you will be asked to be in audiotaped interviews at your home lasting 30-45 minutes each. You may be asked to take part in as many as three interviews. You can choose not to answer a question, stop the interview or stop the recording of any part or the whole interview at any time.

7. What are the possible discomforts and risks?

Talking about death and dying issues may cause discomfort, emotional upset or bring up other issues. The researcher will call the hospice office to report any change in your well-being. For interviews that are done Monday through Friday from 8 a.m. to 5 p.m. a team manager will be called and the on-call nurses will be called after 5:00 p.m. Monday through Friday, weekends and holidays. They will contact the person on the team that can best meet your needs at the time of your call.

If you wish to talk about the information above or any discomforts you may have, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

8a. What are the possible benefits to you?

You may benefit from talking about what it is like to live with a serious illness.

8b. What are the possible benefits to others?

What is learned from this study may help to make the care of people with a life-limiting illness better in the future.

9. If you choose to take part in this research study, will it cost you anything?

There will be no charge for you to be in this study.

10. Will you receive compensation for taking part in this research study?

There will be no payment for taking part in this research study.



11. What if you are injured because of the study?

If you have an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be given to you without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other payment will be offered to you.

12. What other options or treatments are available if you do not want to be in this study?

If you do not want to be in this study, the other choice is doing nothing. If you do not want to take part in this study, tell the Principal Investigator or her assistant and do not sign this Informed Consent Form.

13a. Can you withdraw from this research study?

You are free to leave this research study at any time. If you do not choose to be in the study, there will be no penalty, you will not lose any benefits you are entitled to and the care you are receiving will not change.

If you choose to not to be in this research study for any reason, you should contact Cathy Campbell at (352) 271-9871.

If you have any questions about your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

13b. If you withdraw, can information about you still be used and/or collected?

If you choose not to be in this study the information collected while you were in the study may be used, but you will have no more visits from the researcher.

13c. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

1. You do not meet the study requirements. Ask the Principal Investigator if you would like to know more about this.
2. The investigator decides that being in the study would be harmful to you.
3. You cannot keep appointments or take part in the scheduled interviews.

14. How will your privacy and the confidentiality of your research records be protected?



Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will be kept confidential.

The information received during the interviews and chart review will be kept confidential. A number and the date of interview will be written on the audiotapes. During your interview the researcher may take notes. The notes will also have the same number and date as the audiotapes. No information about you will appear on the tape or cassette case. Only the researcher will have a list that links the number written on the audiotape with your name and address.

A person will type what is recorded on the tape. There will be no information about you given to the typist. The tapes, notes, list of names and addresses and the pages that were typed by the typist will be kept at the university office of the researcher in a locked cabinet.

15. How will the researcher(s) benefit from your being in this study?

In general, sharing research results helps the career of a researcher. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

16. Signatures

As a representative of this study, I have explained to the participant the purpose, what will happen if he/she agrees to be in the study, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Signature of Person Obtaining Consent

Date

You have been informed about this study's purpose, what will happen if you agree to be in the study, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You have received a copy of this Form. You have been given the chance to ask questions before you sign, and you have been told that you can ask other questions at any time.

You freely agree to be in this study. By signing this form, you are not giving up any of your legal rights.

Signature of Person Consenting

Date

REFERENCES

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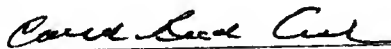
BIOGRAPHICAL SKETCH

Cathy L. Campbell graduated with a Bachelor of Science degree and a Master of Science degree from University of Florida in 1986 and 2000, respectively.

During her career, Cathy has worked as a staff nurse, nursing manager and an administrator for hospice programs in Florida and Washington, D.C.

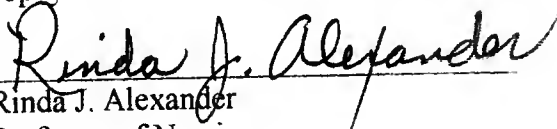
Cathy currently resides in Gainesville, Florida, and is employed as an Admissions Case Manager at Hospice of North Central Florida.

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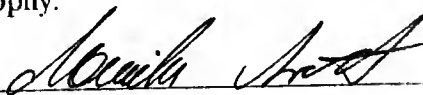
Carol Reed Ash, Chair
Kirbo Eminent Scholar of Nursing

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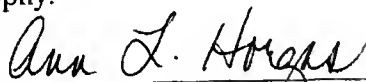
Linda J. Alexander
Professor of Nursing

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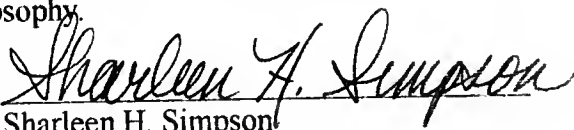
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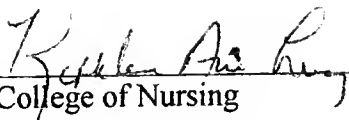
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This dissertation was submitted to the Graduate Faculty of the College of Nursing and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Month & Year of Graduation
May 2004



Dean, College of Nursing

Dean, Graduate School

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